

# **THE MEN'S STORIES**

## **Participant 1 - Jake Stephens**

Jake is a 34 year old man who was born in Lancashire and has spent most of his life in Lancashire or Yorkshire. He was diagnosed HIV positive in 1996 at the same time as his partner, Steve who died after a protracted illness. Jake moved with Steve to a small West Yorkshire market town in 1990 where he still lives and works as a hairdresser.

### *Diagnosis*

Jake's partner had been ill for a couple of years before he and Jake were diagnosed HIV+. One day Jake came home from work to find Steve on the floor 'cuckoo, completely out of it'. He was rushed to the local hospital and Jake was appalled to hear the doctor ask about HIV in the hearing of the rest of the ward.

Steve was discharged and they had 'a good long talk about life and what it means, what we wanted'. It had never entered Jake's head that he might be positive. Steve was drifting in and out of sleep and so Jake made the decisions for them both. When the tests came back positive it was 'an enormous blow...like somebody just switched the lights off...like somebody had whacked you on the head with a hammer'. He feels now that it helped him that everything at the time had to revolve around Steve and he had no time to think about himself.

Although he had been around and been on the scene, he had not seen HIV as something that could happen to him, but in fact what was happening brought him and Steve brought closer together, 'it had to' because by this point Steve was mentally ill. The home nurse came and answered 'all the usual questions', a couple of weeks later Steve got put on treatment but it wasn't until a few months had gone by and Jake had learnt a lot more that it all began to sink in.

### *Changes*

Jake describes the time since his diagnosis as 'one long rollercoaster ride' and at times he felt overloaded. On the whole, though, he believes that his experiences have made him a better person; although he always tended to look at things positively anyway, he has rethought his priorities and small things just don't seem to matter any more.

### *Uncertainty*

One of the things Jake finds hard is the uncertainty of his future: 'It's like throwing a deck of cards up and whatever happens'. New things become questionable; he had just returned from a holiday in Paris and it was in his mind whether that was the last time he would go there.

Harder than the physical symptoms is the emotional up and down that this brings. As a gemini he describes himself as up and down anyway but the HIV makes that more so, so if he gets down now, he gets 'very, very down'. On the other hand, he feels that life is a practical lesson and you just need to get on and live it and this is what Jake tries to do most of the time.

### *Isolation*

Steve and Jake kept themselves to themselves and, following the diagnosis Steve chose not to tell anyone. Jake felt he needed to respect that decision as Steve deteriorated so quickly but it made the whole thing 'very hush hush' which increased the pressure on Jake:

'for three years I had to shut everyone else out and deal with what I was dealing with'

### *Caring and fighting*

Caring for Steve was a big pressure which took up Jake's entire life, a burden made worse by the fact that Jake had to fight the 'system' on Steve's behalf. The local voluntary agency was 'heaven sent' in supporting him in this but the HIV consultant said that she, rather than Jake, had the right to make decisions for Steve:

'I had to stand up and say, well, legally or illegally I will make those decisions'. He and Steve had been together for 7 years and he is convinced that the consultant would have been different if they had been a heterosexual couple:

'She had the monopoly of all the medical decisions...there was only one consultant'. When Jake tried to transfer Steve's treatment to another hospital, the consultant said he was not entitled to make that decision for Steve either, it was 'a nightmare'. Finally Jake called a meeting at the local voluntary organisation with staff, solicitors and the consultant. The consultant insisted that Steve was present even though 'he couldn't even stay awake...he certainly didn't make any decisions...I was absolutely appalled'

Not only did Jake have to fight with the consultant but he had a similar struggle with social services who were also present at this meeting, it felt as if the medical system and social services department had decided to join forces against him:

'I told them in no uncertain terms that I was making the decisions for Steve and what I was doing was the best thing...I was a challenging person, or had to be at the time...the people who should have been helping us both...we had no other option but to have them involved in our lives, were just making it worse...[the consultant] had complete monopoly over everything and wanted it'.

As Jake points out, Steve was facing this as an individual but they were also dealing with it together as a couple. Finally, after about one and a half years of 'absolute hell' Jake was able to transfer his and Steve's medical and social services support to the nearest city which he describes as 'fantastic'. Although he's not 'gay orientated' he thinks it makes a difference that both the consultant and the social worker are gay. He also thinks that he gets a better service in a higher prevalence area where the consultant is more experienced and has access to other specialist health professionals.

### *Death and grieving*

Before Steve died, Jake had had very little experience of death but he believes that HIV opens you up to those sorts of questions anyway, the sorts of questions you have when you're lying awake in bed at night. He feels that his experiences have made death understandable and he had time to reach that understanding slowly during Steve's illness:

'It was as if Steve died from the moment he was diagnosed and then it was just a process of waiting'. Three years was a long time to wait and when Steve finally died in many ways it was a blessing. In his final illness, Steve was transferred to a hospice 'they surrounded us with comfortable clouds really and took all the pressure off' which meant that Jake could spend Steve's last few days 'emotionally' with him.

When Steve died Jake was surprised by how much it hit him:

'it blew me away...I felt lonely...empty...what was all that for?...did it really happen?'

He'd had to be detached from his feelings in order to manage the practicalities of caring for Steve and for much of the time he felt split in two.

### *Spiritual Beliefs*

Steve believed in a Higher Being but Jake doesn't personally:

'I like to believe there's something, but unless I see something...I'm open minded...I am a believer in fate and in whatever is meant to be...whatever happens to you happens for a reason'. He believes that no one can get everything out of life and that if you try to you will just exhaust yourself: 'I think...you just go along with life accepting what comes along

### *What has helped him cope*

Jake says that in some ways he's surprised he's not 6 foot under by now but he thinks the things that have helped have been a solid family, a positive sense of self, the fact that he is a calm, reflective, thinking sort of person and some external help.

### *Changes*

Jake feels that he has had to become more self interested, more ruthless and less accepting of people. In some ways he sees that as a shame. He also feels that, although he was never an impulsive person, he thinks about things more now.

### *The tablets and other therapies*

Jake feels that the pills are there for a reason and is happy to take them, but he also finds complementary therapies useful for relaxation and his general well-being and he has a good relationship with his aromatherapist.

## **Participant 2 - Shaun**

Shaun is a 38 year old man who was born in Leeds but who has lived and travelled extensively in this country and abroad. He lived in Surrey for 2 years before returning to Yorkshire 2 years ago. He now lives on the outskirts of a West Yorkshire market town.

### *Growing up and Coming Out*

Shaun's parents were divorced and he says that he could say that his childhood was horrendous, but it was not as bad as some people's: 'I could have bogged myself down [but] anything negative that's happened in my life I've turned round into a positive thing...people oppress themselves with the past, throw them another negative thing and it will knock them over'

Shaun always had girlfriends at school. He went out with L\_\_\_ because she was the best looking girl in the school and he was the envy of the other lads. He was a 'proper boy' but although he got on with girls, it was just as friends and he 'kind of knew'. When he left school, he felt this pull to experiment and have sex with a man. He discussed it with his girlfriend at the time and 'haven't turned back! I just preferred sex with men' and then he found Paul who was the 'perfect partner'

### *Diagnosis*

Shaun was diagnosed in 1983 when the tests first came out. He and Paul were 'madly in love' and it was Paul who passed the virus on to him. Paul had known he was positive but at the time there was very little publicity about unprotected sex; it was not until his brother was diagnosed with AIDS that he realised that Shaun might also be infected. Shaun's response was 'It's a virus, deal with it. It's like a cold really, if you look after yourself you're going to survive this'

### *Coming back to Yorkshire*

Shaun returned to Yorkshire following the death of his partner 2 years ago and he describes coming back as 'dreadful' because of the different lifestyle and the fact that HIV is still a taboo in the area.

### *Time*

Shaun is acutely aware of the value of his time; he says 'I don't have time to mess about'. He lives in the present, taking each day as it comes, although he still has plans and goals for the future; he wants to buy a VW camper and travel Europe with his two dogs. He believes that he may well live the full extent of his life but in the meantime he needs to have little goals, something to look forward to.

### *Shaun's community*

Shaun describes his community as 'backward', compared with where he lived in Surrey where people were 'more intelligent and you can talk about all kinds of things, here there is only one level of conversation...no disrespect, I'm a northerner myself, but they have no initiative, they don't get off their arses'. It is an old mining community, very working class and a bit of a backwater. Shaun is aware that gossip goes on about him in the local pub; 'it's the same everywhere you go...it's basic pub

tittle tattle'. He takes a matter of fact approach to local attitudes; he says he doesn't 'give a damn who knows about his status: 'It doesn't affect me, it gives me a lot of strength, people are just so ignorant...if you can't get your head around gay people and HIV I feel sorry for you'

### *The gay community*

Shaun places himself outside the gay community, both in London and in Yorkshire; most of his friends are 'just regular people; I don't see myself as a gay man, just a regular man who happens to be gay. It's done me a lot of good not to be stuck in a niche...every human life has its individuality. In this society I'm called gay and HIV+ but I'm human in my own way'.

Shaun spent some time in San Fransisco where he found the gay community 'very frosty...very up its arse...it was hard to make friends, people assumed you wanted to sleep with them, you can't chat, they think it's chatting up...it's a copping off environment and that gets in the way of everything else. I don't knock the gay scene, the scene and the gay community have their purpose...it's very supportive for some people who need that to latch onto'.

Shaun says that the local gay community is very strong on a Sunday night, in the gay pubs at the 'dodgy end' of town. He describes it as cliquey where you can't set a foot wrong: 'If I went in there and fell over, people would be talking about it two weeks later'

### *Medication*

Shaun had started taking combination therapy in the week prior to my visit, largely because he was feeling very fatigued and he wanted more energy in his life.

### *Professional services*

Shaun felt very frustrated by the services in Yorkshire when he compared them with his experiences in London, he feels that the services and information are not necessarily accessible and if people do not know what to ask for and how to ask for it, they may go under. In Surrey, on the other hand, someone would keep in contact with him and his partner just to check they were OK, but particularly Social Services in the area were not geared up for HIV. Shaun says that a social worker visited but did not have the relevant information so he went above her head to the Head of Social Services:

'If I need something, I won't give up but most people around here would...I battled...and wouldn't take no for an answer...I knew I'd win in the end...I know my rights...and I'll stick to what's rightfully mine'.

The Head of Social Services promised Shaun services which don't exist and Shaun is still arguing the point with him, for example, regarding respite. He also had great difficulty when he first moved to claim the appropriate amount of Housing Benefit: 'They were just bombastic and damn well difficult'. Shaun believes that part of the problem is that people in Yorkshire are not as demanding or don't know what they're entitled to'

### *Voluntary organisations*

Shaun feels 'oppressed' when he goes to meetings because there is nothing positive from other people. He also feels that people treat him with 'kid gloves'; they are not sufficiently clear or pro-active about what they are offering but at the same time are intrusive 'but I do need them at the end of the day'. One voluntary organisation funds his acupuncture but that arrangement was not straight forward either as Shaun had found his own therapist.

### *Medical Services*

Shaun was diagnosed in Yorkshire in 1983 and was given his diagnosis over the 'phone which was 'quite barbaric'. There was a group meeting 'where HIV people were thrown into a room to chat about how poorly they were...[I realised] I could become that person or just crack on'. He doesn't go to his local HIV clinic because the consultant there is 'a typical doctor who's right...a real pill pusher who puts the fear of God into people...not giving personal choice in my opinion.' He went to see her twice, both times they lost his blood and she wouldn't even tell him this herself so he said to himself, 'Use your instinct; who's good for you' and transferred his treatment to a larger treatment centre in South Yorkshire which is a 45 minute journey from his home.

### *Death and grieving*

Shaun's partner had died 2 years ago and his brother, Chris, 6 months before that; he was one of the first people to be diagnosed in this country. Shaun and his partner were together for 15 years in a 'lovely relationship'. Shaun's brother was treated with several drugs in experimental stages and Shaun says 'I didn't see the quality in his life'. Paul was first diagnosed with lymphoma, then pancreatitis (twice) and finally liver cancer. When Paul died, Shaun was sad but did not want him to suffer; he died very quickly and was not in any pain.

### *Health*

Shaun says that his health began to deteriorate about 7 years ago as a result of stress due his partner's deteriorating health, but he still believes that he has got quite a few years left. His health has recently taken a bit of a down turn as a result of stress - two deaths within a short period and two house moves: 'I didn't put myself in stressful situations, I was in stressful situations'. The result is that his CD4 count has fallen, his viral load has risen and his platelet count is low. This is not a shock but it has tipped the balance for Shaun as regards treatment because the fatigue is stopping him living life the way he wants to. At the moment he has to go to bed at 9pm and still wakes up very tired. He doesn't want to start but has decided that he should given the quality of his life. He has talked a lot to other people but of course realises that 'their stories are different and mine will be different as well'. The doctor advised him to start but left the decision up to him: 'My instinct said yes'. Nevertheless, he began to panic as it came to the time of his first dose, then he decided 'You've set this time, now just get on with it, just do it'. He could certainly feel them going in to his system but he is looking forward to the increased energy which he hopes they will give him: 'I eat well, I look after myself well, and I think the medication will work well with me'. If there is something wrong with him, he doesn't immediately assume it is HIV related and when he is down, he holds onto the belief that it will pass and in the meantime he will do what he can to alter the situation.

### *Complementary treatment*

Shaun is happy to go to the doctor for a diagnosis but likes to use alternative treatments, particularly acupuncture. He had an old dog and the vet advised him to be put down but he was treated with acupuncture and was immediately better. Shaun understands acupuncture and totally believes in its beneficial effects, that it releases energy to flow through the body.

Shaun is able to balance orthodox medicine and complementary therapies but has been criticised for starting combination therapy by a friend who has been giving him a herbal tonic: 'she doesn't have an understanding of HIV...I've got this little army of virus in my body...I've got to attack it at another level now'.

### *Family and friends*

Shaun is very close to his mother and one of the reasons that he moved back up north was to be nearer to her. He doesn't see his father as it is 'not worth the effort' and he doesn't see his siblings often either - he says they want him to be interested in their lives but they aren't interested in his: 'I've got my own agenda - it's selfish but not malicious'.

On the other hand, Shaun's friends are 'very dear and loyal' and a crucial source of support; 'They know I won't burden them unless it's totally necessary, usually we laugh at stuff, lift it up and lighten the burden.' His friends are scattered across the country but Shaun uses the internet to keep in touch with them and also for accessing information about HIV.

### *Work*

Shaun gave up a successful career to look after Paul but now is giving some thought to going back to work, possibly in the HIV field 'I'd need to do something that's more in the flow of what's going on in my life now'.

### *Spirituality/outlook on life*

Shaun's understanding of HIV is integrally connected to his holistic philosophy of life: he believes that HIV is man-made, a result of our polluting effect on the environment. This helps him to get a handle on it and also gives him hope; if we've done it, we might be able to reverse it.

Shaun believes that people latch themselves onto a religion in order to be told what to do. He thinks there is life after death but prefers to reach his own conclusions. He believes in the law of karma: 'You drop a penny in a pond and the ripples go out and come back again'.

Shaun feels that he holds responsibility for the quality of his life:

'The quality of my life has been very good and it's been me who's been in charge of that...it's only me that can look after me...I'm lucky...gifted....I sail through life...make the best I can with what I have...It's survival at the end of the day'.

### *Effect of HIV on life*

HIV affects Shaun on a daily basis, particularly as a result of the fatigue he experiences 'but not so that it stops me being a strong person and living in a



community'. He also says that he has to look at life in a more serious way. 'I looked at my life and looked at the negative things and turned them into positives, looked at my life practically...I don't attach any blame to anybody, anything or anyone'.

### *Home and daily life*

Shaun's home is very important to him as he spends a lot of time there and he needs a work room to work on glass and stained glass. He is also keen on working in his garden.

On a typical day he will set himself at least one job. He wakes at 5am, dozes until 7am when the dogs wake him up. He has breakfast and walks the dogs. On a Wednesday and Friday he goes to the gym which gives him energy and a structure, but he gives himself the opportunity to relax in the afternoon if he needs to. He does most of his jobs in the morning, sees how he feels in the afternoon and by about 3pm he will begin to unwind and maybe read a book. He will eat at about 7pm, have a glass of wine and go to bed at 9pm. He says that he still drags himself around on bad days and it is frustrating because when you look well people don't realise that you feel awful.

'I've always done my own thing - I drove my mum mad!'

### **Participant 3 - Robert**

Robert is a 31 year old man who was born in a small West Yorkshire town. He travelled and lived in London where he was diagnosed in 1990. Soon after his diagnosis he returned to Yorkshire where he lived in a small village near his parents. At the time of the interview he had recently returned to work and moved in with his HIV negative partner on the outskirts of a West Yorkshire city. Robert and I know each other from when I was working in Yorkshire.

#### *Growing up*

Robert had a strong born again Christian upbringing and felt terrible about his feelings of difference. There were 'the usual playground taunts' and he remembers a sexual health lesson where the teacher said 'I'd rather be in the room with a homosexual than with a rapist'...'I didn't really understand either but I knew rape was bad, so I associated gay with an imprisonable, horrendous thing' and his early experiences with men were 'awful, really bad' and so just confirmed these feelings. After a short period in the army he found himself with no money and nowhere to live and soon began to sell sex in London. 'I didn't want to but I just carried on, almost like a job', telling himself that really he was straight and only doing this for money. He then moved to Holland and worked in the sex industry there until he was about 18 when he got back involved with the church. He joined a church which promised that he could be 'healed' of being gay and later moved back to England, still under the influence of the church: 'I paid heavily on guilt'. After entering a relationship, he left the church once again but 'I was confused, messed up' and he and his partner soon split up. Robert then started work in a jewellers shop, mixing with lads from the sex industry but not doing any trade himself - 'independent but still a part of that culture...just knew people around that scene'.

#### *Friendship*

Robert formed a friendship with another gay man which was 'completely opposite' to his experience so far: 'He was intellectual, stylish, attractive, he cared deeply for me as a friend and I admired him immensely...I never really understood why that relationship occurred'. This friend showed Robert kindness and acknowledged him as a person rather than as a sex object or potential religious convert. One day Robert got a 'phone call at work and his friend asked him to visit. 'I'd seen him 1 or 2 weeks before and he was OK, but he wasn't OK, he had AIDS'. He died just a few months after Robert was diagnosed: 'Even now it really breaks my heart, there was so much left unsaid'. The friend's parents took over and Robert was not invited to the funeral; there was no opportunity to say goodbye.

#### *Diagnosis*

Robert started to think about his own actions; he had believed that you could tell if people were infected, and although he'd had protected sex, quite a lot of the time it hadn't been. He believes that, if the result had been negative, given his history and internalised homophobia, 'I would probably have left London and gone back to Yorkshire and never been with another man ever, but it weren't like that...I would have thought...what a lucky escape, keep away from those dirty, filthy gay bastards who have killed my friend...I hated myself and I hated gay men' but actually the only support at the time around being positive was from other gay men.

Robert describes the gay scene bitterly: "You're a young chicken, meat on the rack to be used...you're a score, a notch...I hated gay men, I hated what I were doing...If there were anything I could have done to stop being gay I would have done it'

### *Moving back to Yorkshire*

Robert decided to move back to Yorkshire: 'there was nothing left in London; I lost my job, P\_\_\_ wasn't there, where would I live? Who would care for me? They told me I could die within a couple of years, it were a natural step to come back...pretend the HIV wasn't there, I wasn't there...brush aside the whole past'

Robert saw a counsellor who was 'brilliant...incredible compassion in his eyes...he broke the gates open' Robert feels that even now he has not worked through the abusive experiences he had early in his life. When the counsellor asked what Robert would do if he was offered an invisible pill which would stop him being gay: 'I'd bite your arm off!'

Robert then started a relationship with a man who treated him badly and finally Robert ended the relationship: 'It was the first time I'd stood up to anyone and it hurt like mad...I were really confused, messed up, drinking a lot, playing the system for all it were worth.'

### *A new relationship*

When Robert first met Ian he decided he would protect him from 'that bunch of vultures' - the gay community: 'It was not love at first sight, but one day you wake up and realise, I love him'. This seems to mark the start of Robert accepting his sexuality, and after a couple more years of counselling, when he was once more offered the invisible pill, Robert's reply was 'You can stick it up your arse!'

### *Village life*

Robert had been housed in a block where there were some drug users and for a while he had a phase of IV drug use. He says that, now he had finally begun to accept being gay, he had something else to punish himself about. He moved to a small village to make a new start and is furious that he had been housed in what he sees as 'a problem flat'.

In the village he was housed 'with old people, I was singled out...the walls were like paper and everyone knew your business.' He was on a lot of benefit but had nothing to do.

Soon after moving he developed thrush, a fungal infection, bronchitis and PCP and was admitted to the local hospital. Robert was angry about what people were saying about him in the village: 'You only got arse end of tail...you knew people were talking about you...it affected my life so much being on benefit...in that village...I ended up being in a prison, not to be seen carrying shopping, walking...you live up to expectations of being unwell and it made you unwell...some of it was point blank paranoia and some of it was very very real.'

Robert believes that there is a widely held link in people's minds between gay men and paedophiles which is more prevalent in a rural area where there are strongly held

prejudices about how people should behave and what sort of relationships they should have.

Robert was recently the victim of homophobic violence from a stranger who asked if he was gay and then hit him in the face. The police's response was 'he just hates everybody'. Robert says they assume homophobia doesn't exist and compares it to racism which is now more recognised... 'It will be a long time before gay men's lives are valued like other people's.'

### *Moving house*

After 18 months Robert moved to a different house in the village and he identifies this as the 'beginning of claiming myself back, turning it round, being happy about being gay'. He lived there for four years.

### *Lazarus*

The advent of combination therapy meant that Robert 'wasn't dying any more...I couldn't get away with not having responsibility for my life...it got harder and harder and harder...to not be doing anything with my life.'

Robert got very anxious about living in the village as a benefit claimant and believed that his neighbours reported him to the DSS on at least one occasion: 'I think it's because I'm HIV+...people don't like gay people round here'.

Robert didn't feel he couldn't trust a local consultant so he went down to London to discuss his options regarding combination therapy:

'I were gutted, I walked out that hospital. I got plastered. I couldn't believe I'd spent all that time...fighting benefit...guilt...only to be told by some silly arse, it's fine, you're going to live...that was almost as hard...that realisation that this therapy worked was as hard or harder...because the living's almost as painful as the dying.'

### *Back to work*

It was a long process and Robert describes himself as 'kicking and screaming' and as having no practical support. His counsellor suggested that he built on the facilitation work he had already done so Robert did a course on group facilitation: 'I want to work! I want to live! I were liberated!' He got a placement at a local HIV organisation and applied for a job at another which he didn't get but he was given very positive feedback from the interview:

'I was not so much of a right off as I had allowed myself to believe and other people had allowed me to believe, the doctors, society, the HIV industry...my disability wasn't physical; My disability was being a decade out of the system, being dyslexic, being computer illiterate, having low self esteem'.

He found it enormously frustrating that he was not able to get clear advice or information about the effect on his benefits of returning to work 'You're telling me...I have to be in work and if that's the case, that's exactly what I'm going to do and if it makes me ill and if it kills me then you lot can bear the brunt of it.'

Robert has now got a job at a local organisation for gay and bisexual men. He finds aspects of work very hard; getting into the routine of getting up, dealing with work relationships, going at a speed which fits the organisation, getting enough sleep, sticking at it.

#### *Partner's injuries*

Robert was extremely shocked when his partner was involved in a serious road traffic accident and was badly injured, 'it makes you suddenly realise how much you do have'. Suddenly the tables were turned and it was Robert who was the carer.

#### *Anxieties*

Robert is anxious about what will happen to him if he becomes ill in terms of his benefits and because the local HIV agency has shut. He is angry that his Housing Benefit has been withdrawn so he has had to move in with Ian and he is on too high an income to access funding for respite. On the other hand, he says he feels 'proud, justified, acknowledged; a lot better about myself...I am unique...in my resilience, perseverance and determination to carry that through...I'm glad, even if it doesn't work out...that I managed to gain what I knew I could do.'

#### *Gay community*

There is a small gay community in Yorkshire but if you live outside the city it is virtually impossible to access without a car. There is one club and one pub for a large catchment area, and these and PSE's (Public Sex Environments) are your only choice for meeting other gay men. Robert says that people go to PSE's to avoid the gossip which occurs on the scene; he says that if you have more than three partners 'you're a slapper' and if you are positive it is almost impossible to keep it private; at PSE's there is little or no discussion and no-one talks about what goes on. Robert says that if you are positive there is an expectation by other gay men both that your partner must also be positive and that you carry more responsibility regarding safer sex.

#### *Benefits and drawbacks to living in Yorkshire*

Robert stays in Yorkshire because property is cheap up north, he can be near his family, have a better standard of living and have access to beautiful countryside. He does, however, think that the services are better in London, and that it would be easier to get and keep a job. In particular Robert is critical about the services in Yorkshire:

'I don't believe that the people shouting about the services here in Yorkshire have any idea of what's going on for a lot of positive people and I don't actually think they care'

#### *Living in a serodiscordant relationship in Yorkshire*

Robert says that there has been little support, information or advice for his partner and he is aware that issues around his medication, its side effects and the depression he experiences take a toll on him 'I don't know what all his needs are...he needs help to ask me for what he needs'. Negotiation around sex took a long time and was hard for them both: 'sex has always been complicated and there was a lot of fear, knowing that there could be a risk'. He feels that professionals still hold an attitude that if you are positive you should abstain from penetrative sex altogether.

Robert also feels that partners are often not supported by the gay community either; he realises that he has behaved in ways which would warrant a split but 'if Ian ended

the relationship, he would be demonised by other gay men and would pay dearly in guilt'. Robert feels that his partner will only be recognised when Robert is dying, but that now he could be supported to play a more active role in helping him with adherence issues.

### *Medication*

Robert has a long standing love-hate relationship with combination therapy, partly because of his suspicion of its efficacy and partly because of the difficulties of facing a renewed future which Robert had adjusted to losing. He has also suffered some debilitating side effects which he feels the doctors don't take seriously: 'they're middle class, upper class with high salaries; they live in a totally different world to my world'. Robert feels that combination therapy is being promoted as the answer and gives people a false sense of security

Robert finds it difficult to remember his medication and he resents the pressure he feels to take combination therapy, but on the other hand, he would welcome a feeling of direction and purpose that being back at work can give him. At the time of our second interview, Robert's last blood results were not good and he was in a position of feeling he would have to do something although he wasn't sure what. Even though he had taken his medication as 'blip therapy' he is not at this point viral resistant to any of the drugs. 'I will be addressing this, watch this space'.

### *Other services*

In addition to his counsellor, Robert has found massage very beneficial

### *Spiritual beliefs*

Robert has stopped believing that he is guilty, a sinner who needs saving. He still believes in God and the responsibility one holds to be good to oneself and to others but he follows different strands of spiritual wisdom rather than one faith. He believes in the law of karma - if you are kind to others, kindness will be revisited on you 'I hope that the good things I've done come back for me.'

### *The future*

Robert finds the future scary because he is on the verge of getting involved in therapy again and work is a difficult process to get into; he finds himself living on less money, less acknowledged but more spoken about, judged wrongly by other positive men. He is frightened by the government's back to work policy 'without doing shit dilly about what happens if someone gets sick again.'

### *Daily routine*

Robert gets up at 6.30 - he feels rough in the morning and it takes him a while to come round. After a few cigarettes and coffees he gets the bus or train to work. He may be based in the office and he may travel in the course of his working day. After work it is 'tempting' to go to the pub with colleagues 'for support' but this has caused friction with his partner over his drinking. He'll then go home, have something to eat and go to bed at about 10.00. He feels he is getting run down and wonders if part-time work would be more appropriate, he would also like a job that wasn't so focused on HIV.

## **Participant 4 - Nick**

Nick was born near Ipswich but has lived in various places and travelled widely. He was diagnosed in London five years ago but now lives with Tony (participant 5) in a village just outside a West Yorkshire market town.

### *Growing up*

Nick knew he was different when he was 6. He remembers a hot summer when he and his friend were in their swimming trunks playing when his friend fell down. Nick picked him up and wouldn't let him go. He was painting his nails at age seven and by age 14 or 15 he knew that he was gay. His first sexual experience was when he was 15 and, although he didn't tell his mother until he was 19, three years before she had told him 'you're either going to grow up to be a pervert or you're going to be gay'. Nick has a gay uncle and when he was younger he wanted to spend time with him but his father prevented it as he was afraid 'it would turn me gay'. Nick told his father that he was gay and HIV+ at the same time 'which hit him hard' but, apart from his older brother, now the rest of his family would do anything for him.

### *In the closet*

Nick hid the fact that he was gay and got engaged 4 times. Six weeks before the wedding he tried to sleep with his fiancée (he had slept with men but not with women) and he simply couldn't go through with it. He pretended he had a migraine and three weeks later he rang his fiancée, told her he had had mumps and was now infertile. The wedding was off and since then he has been open about his sexuality.

### *The navy*

Nick joined the navy which he absolutely loved, but he was forced to Come Out when he found his partner on the 'phone to his divisional officer. What followed was 'the most degrading thing ever...one of the most horrendous things I've ever been through'; he had a 6 hour interview, they searched his address book, his pockets, they contacted his friends, they questioned him about his sexual life. They thought that he was using being gay as an excuse to get out of the navy 'but I loved the navy; I'd go back in tomorrow'. They remained unconvinced and subjected Nick to a medical examination and a disciplinary hearing before they finally kicked him out. Nick says that, in comparison, telling anyone else was easy but his ordeal still didn't affect his sense of self: 'I was so sure of what I wanted and what I was, that nothing was going to change that...I am gay and that's the way it is.'

All his colleagues were told that he had been done for drugs but as Nick walked out in tears, someone said 'We know it's not drugs...just letting you know...we don't agree with it, we think it's wrong' and everyone applauded him as he walked through the gates 'howling'. For 2-3 weeks he wished he hadn't done it 'and then I picked myself up and got on with it.'

### *Getting tested*

Nick had a friend who died as a result of AIDS in 1987, who made Nick promise that he wouldn't get infected. Since that time Nick went for 6 monthly tests: 'Every time I came back negative I felt guilty; I should be positive...This one, I knew it was positive...as soon as I got to the doctor's surgery door I knew I was positive'.

Nick went straight from the doctor's back to work. He and his partner coincidentally split up two weeks later, not because of Nick's result. 'I've never really been down about it, I've just got on with it...I've always said I would never let it run me.'

### *Medication*

Nick first started medication when he was living in London, working and still feeling healthy. He became so ill that three weeks later he couldn't get out of bed, he had lost his job and was on benefit. 'I couldn't get out of bed without being sick, couldn't go to bed without being sick...I was so ill'. He persevered for a few months before he told his doctor he needed to stop the tablets. The doctor's response was that if he stopped taking the tablets he would stop signing his sick notes, i.e. he would sign him back as fit for work. Nick decided he wanted his life back. He flushed his tablets down the toilet and 'within two weeks I was back on my feet...I could do anything.'

Nick went to Ibiza to celebrate coming off the tablets, met someone while he was out there and moved to West Yorkshire. He now goes to a South Yorkshire Clinic, not the local one about which he has heard 'horror stories.'

Nick went to Egypt two years ago and on his return was hospitalised with pneumonia, he refused to start HAART despite a lot of pressure but went back to work too soon, got shingles in the optical nerve and lost the sight in one eye. He gave way under pressure from all sides to start HAART:

'I hate them. I hate being on them. It feels like every time I take the tablets it's ruling me and now I haven't got control of it any more...I'm not taking the drugs because I want them...I'm taking them for everybody else...If I could get away without taking them I would but Tony (partner) always knows...I felt I had to because no one would listen, absolutely no one was prepared to see my reasons, my point of view.'

He doesn't actually feel any different on or off the tablets but his test results have shown a massive improvement.

Before his diagnosis, Nick was always reluctant to take medication and he feels that adjusting to the drugs is the hardest part of the whole process. He believes that if he had chosen not to take combination therapy he would have greatly distressed his family and Tony and also he feels that the medical services would have given up on him. He compares the attitudes of people who separate the 'innocent' (babies and haemophiliacs) from the 'guilty' (IV drug users and gay men) with the split between the 'responsible' (take combination therapy) and the 'irresponsible' (avoid medication).

'I just hate them full stop. Every morning I take them they stick in my throat, every night I take them they stick in my throat...I've always said this wasn't going to control me. Now I feel as if I've lost control because of the drugs...I've lost that battle...I've just got to get on with it and take them, even though I hate it...I still think maybe a couple of years down the line I'll decide not to take them anyway. I'd like just to throw them all away today, stop them and never take them again'. Nick is anxious that people see combination therapy as a cure. He believes that, with people living longer, there will be a 'mass explosion' of HIV and AIDS in a few years' time



### *Living in Yorkshire*

Nick says that everyone around knows he and Tony are gay, but there's no real hassle. He actually says that there is more homophobia in the nearby city and he thinks that the acceptance he experiences locally is because the gay scene is more integrated with the rest of the community. As far as a gay community is concerned, there is a good local gay scene on a Sunday night which attracts people from all over the country; in fact different days are associated with different towns. Locally there are two pubs but there is room for another one or two, especially as the gay pubs also attract straight couples.

One of the main benefits of living where they do is privacy and Nick couldn't think of any disadvantages; you are able to keep yourself to yourself. 'We tend to like to get away, close the door and know that no one's going to be knocking on it every five minutes'. He likes the gay scene in Leeds and his partner likes Sheffield so they take it in turns to choose where to go. The Leeds gay bars are divided into two; there are the 'Versacci and D&G bars' and the others which are 'common, down to earth, sawdust floors'. Tony finds Leeds 'too crowded' whereas Nick finds Sheffield 'boring'. In London there is more choice but Tony compares Yorkshire favourably to another rural county where there is one gay bar for the whole county! He says that there are little gay scenes in Leeds, Bradford, Sheffield, York and Hull.

### *Services*

Nick is angry with the benefits system; he had a friend who committed suicide after being refused DLA. He has not had many dealings with voluntary organisations up north, but he feels that the London ones are bigger and go more out of their way to help, also 'other people are so down in the dumps when you go there' a lot of people with HIV who are working and getting on with their lives simply don't go. He sees a couple of people at the local HIV agency who he sees partying on the scene but they don't go out to work and they are 'really glum' at the drop-in. Nick, by contrast, has a very positive attitude to all of it 'I just get on with it'.

Nick is also quite sceptical about complementary therapies which he thinks only work because people believe that they will.

He is very happy at the clinic he attends in South Yorkshire but wishes that they would do evening appointments so he wouldn't have to take a day off work; at the moment he has to lie at work about where he is going and it cuts into his annual leave entitlement.

### *A positive attitude*

Nick retains this positive attitude even though he was infected as the result of a gang rape at a party and what happened was totally out of his control, so he feels intolerant of people who, for example, blame their partners for infecting them.

'The only time it comes to the forefront is when someone's whingeing 'My boyfriend gave me AIDS, blah blah blah'... I had no choice in what happened...I think that made me more of a strong person...After that I took control of everything...It's just one of those things that happened is the way I look at it now, it just happened and nothing can be done about it...I've taken control of my life.'

Nick feels that living with HIV has made him a lot stronger, he doesn't allow things to get to him any more, he accepts himself as he is. He has also learnt to put himself first 'in a good way'; if he doesn't want to do something he simply won't do it.

For the first couple of years Nick says there were times when he was depressed 'but you can't carry on like that. It's happening! Get on with it! That's my attitude'. He believes that the reason why he is still so healthy is because he hasn't let HIV get to him.

### *The future*

Nick has never had a sense of a long term future; when he was seven he said to his mother 'I'm never going to be 40 and you'll go to my funeral'. He doesn't feel he will become and doesn't want to become old; he lives for today and the only thing he plans ahead for are holidays. He is buying a house with his partner 'because we want to today...If Tony dies in five years' time...if I'm with Tony in five years' time, it's just part and parcel; it's life'. Nick has never owned a house before because he has moved around so much and it feels like a big commitment, but even if they split up he is sure they could work something out. 'It's about time I had something steady in my life...buying this house is going to be a big first thing I've had that's solid...I want to do it...but...I can't just turn round and walk away, but I'm also willing to take that step now, settling down, getting a strong hold somewhere.'

### *Work and confidentiality*

Nick works in the catering industry where confidentiality is essential: 'In that sort of trade if anybody knows you'd be out on your ear'. He is able to keep his work separate from the rest of his life and very few people at work know he is gay. Nick says that the only time HIV rushes to the forefront of his mind is when he cuts himself at work. Even though he knows he doesn't expose anyone else to infection, he is afraid of anyone seeing him bleeding. His biggest fear is if anyone found out at work - 'It would end everything.'

Nick lived with and chose not to tell an ex-partner his status, partly because he could never find the right time and because he feared his partner's reaction. His ex found out through someone Nick didn't even know. This person had heard a conversation a couple of friends of Nick's were having in a pub down south about Nick going back onto combination therapy. They then decided to tell Nick's ex. Nick doesn't blame his ex for being angry but 'will kill that bloke if he ever sets foot in Yorkshire again'.

Nick was relieved when he disclosed his status to Tony and found out he was positive too, although he wouldn't necessarily go out of his way only to date positive people. After some negative experiences he decided not to tell people any more. The last person he met was a man of 17 or 18 who's response was 'Well it's about time I had it' which profoundly shocked Nick 'I never ever expected that reply from anybody...It just blew me out...he had his whole life ahead of him'.

### *Daily life*

During the week Nick gets up, has a cup of tea, forces down some breakfast which he needs to have because of his tablets and sets off for work. Once he comes home, he watches TV for a bit, cooks tea and watches more TV.

At the weekend Nick relaxes; he finds his job quite tiring so he will watch TV, do a bit of shopping and usually Tony will cook unless they have visitors.

### *Spiritual beliefs*

Nick doesn't believe in Heaven and Hell but does believe that this life is a teaching period for something greater; we learn the lesson we have to learn for this lifetime, die and move on to another lesson. He sees HIV as simply 'a complication' in this scheme; 'I'm still going to learn my lesson and once I've learnt it I'm still going to die...we're here for something that's out of our control and we're here to learn this lesson and then we'll die from whatever.'

He had a dream that he was re-tested HIV negative and the only way they could find out how he had been cured was if he died, so he committed suicide so everyone else could be cured. Nick believes that a cure will be found, but in the meantime 'I don't think we're doing our bodies a lot of good keeping on pumping the drugs into us.'

### *HIV within his relationship*

The different ways in which Tony and Nick live with HIV can cause difficulty within their relationship, 'to me it's not there...to Tony it's a third member.' Tony thinks and talks about HIV much more than Nick, finding out as much information as he can. 'I shut it out and forget about it whereas Tony will look it up and research it'. Tony's anxieties about his lypodystrophy has also caused difficulties between them.

### *Limitations of being HIV+*

Travel is a limitation, particularly to the US and Nick finds also that he gets tired, although he realises that this might just be a case of getting older.

### *Death*

Nick has made plans about his funeral. He wants his ashes scattered in the sea and everyone to have a party with a drag queen act. He particularly wants to avoid people feeling they have to visit a grave or memorial 'Once I'm in the sea I want people to think, he's where he wants to be, he's at rest, and forget about it...This is a shell. When we're finished with it, we're gone.'

On the other hand, Nick isn't ready to die just yet, but he does believe that at some point in the future he will die as a result of AIDS 'I know it's going to happen but it doesn't prey on my mind.'

## **Participant 5 - Tony**

Tony is a 33 year old man who was born in a village just outside a West Yorkshire market town. He lived in the village in the same house until he was 25 when he met 'the love of my life' and moved away for 5 years. He was diagnosed in 1992 and spent some years caring for his partner, Peter, who died as a result of an AIDS related condition three years ago. After his partner died he moved back. He bought the house from his mother and now lives with his partner Nick (participant 4). He works in a financial job in the nearby city.

### *Growing up*

Until he was 15, Tony didn't have any concept of what gay was; he would see Larry Grayson on the television and know that he was gay but didn't understand the meaning of two men having a relationship. His parents were Catholic and although it was never talked about there was an understanding that being gay was disgusting. He knew something was going on when peers started 'courting' and he wasn't interested 'but I didn't put two and two together and get anything really.' He had his first experience at 15 which he found pleasurable. He was an older guy from the village, he could perhaps have been classed as a paedophile; guilt set in for a couple of years after that and he knew no one else from his age group who had had that sort of experience. He had one or two experiences at school but it was not until he began work in Leeds that he Came Out.

### *Coming Out*

At age 19 he found a gay pub and 'once that happened there was no stopping me'. Once he met other gay people he had no difficulty accepting his sexuality. It was, however, still a big taboo at home because of his mother's prejudice; when his sister had an abortion at age 17 she 'hit the roof'. He says rather wryly that all the things she did say and that they were brainwashed into believing turned round on her - his brother and his sister both lived with partners without marrying them, his sister had an abortion and he is gay. It 'turned all her beliefs upside-down'.

Tony says he didn't really want to be gay because he knew it would be a much harder life but he accepted it early on. He remembers a lad on Brookside about his age who was gay who was a role model 'God forbid you wanted to be like him but that's what you followed' in the absence of any alternative... 'I didn't know about homosexuality at all in a non-freakish way. I knew about it in a camp way - Larry Grayson, Kenneth Williams, but not about two men having a relationship, having a bond.'

### *HIV*

Tony blames getting infected on that naïvity. He thinks he was infected when he was 22 or 23. He had heard about AIDS on the television but he didn't know it was prevalent and he didn't know what a GUM Clinic was; he thought HIV only affected people in London who were living the high life.

Once Tony had Come Out being gay became just a part of life but still HIV was not discussed on the scene. He compares Peter and he having to be secretive about their diagnosis with being back in the closet. And again, once Peter died and Tony contacted the local HIV agency, he is beginning to realise that being HIV+ doesn't

feel so much of a problem - 'it's like a second Coming Out, and a positive one to a certain extent'.

### *Diagnosis*

In hindsight, Tony believes he was infected shortly before he met Peter, but at the time he was 'HIV naïve, gay naïve' and didn't really think that much about it. Peter was 13 years older and Tony put his lack of energy down to the age difference between them. Then he developed thrush and visited a consultant but didn't suspect it could be HIV. He was tested and Tony was told the result and also advised to be tested. Neither of them received any pre-or post-test counselling. Tony had never been to a GUM clinic before and was 'absolutely devastated'. He had only recently recovered from another medical scare when his father had been diagnosed with Huntingdon's chorea and there was a 50:50 chance he could have passed it on to his children.

Peter had a CD4 count of 40 at diagnosis and this was the start of him becoming ill. Tony tried hard to get information but there was little available and what there was was negative so they just cut themselves off and got on with it as best they could.

### *Family*

Tony's mother is a staunch Catholic and Tony had decided not to tell her he was gay. That Christmas, however, unbeknownst to Tony, she saw him and Peter (who had been introduced as 'a friend') kissing. 'I got the silent treatment for a month. Peter suddenly got a kidney infection and became seriously ill but when he recovered, his mother asked Tony if he was gay: 'Yes, and has Peter got AIDS, yes, and I'm HIV+'. She gave him two days to get out. 'Her attitude was probably fairly typical of round here'. Tony moved out and in a couple of weeks she contacted him. 'She must have done a lot of soul searching; she didn't like it but she was prepared to put up with it...It was a real feat that she turned round in the way she did...I didn't believe my own mother could think or say the things she did.' Now she knows he's gay, she loves Nick but she doesn't see it as equivalent to a heterosexual relationship and Tony found that very difficult when Peter died.

### *Caring for Peter*

Peter and Tony moved in together, which was a very freeing experience for Peter who, at 39, had lived with his mother all his life and was still very closeted. Although he remained closeted, he was now living as a gay man. They lived on a farmhouse in the middle of a field 'and just got on with it'. Peter deteriorated over the next three years as he got infection after infection. He had a brief spell of renewed health on AZT when they went on holiday and 'did all the things of a lifetime' but Peter 'built up a barrier and never accepted the fact that he was going to die'. On the other hand Tony was well informed by now and knew how poor the prognosis was. His own status was totally background; caring for Peter took all his time and attention. Peter would recover from one infection only to succumb to something else and during this period they got little or no support 'we just existed...going from one thing to another'. They decided to move into the town to be nearer the hospital 'I was enjoying living where I was...we had cats, wild cats, one of these places you fall in love with' but they decided it was in Peter's best interests to move into town. Very soon after they moved Peter's health deteriorated rapidly; he was diagnosed with non-Hodgkins' lymphoma.

'I thought I'd been struggling up to this point...and then I just didn't know what hit me.'

The doctors decided that it was in Peter's best interests not to tell him he had AIDS or cancer. This went on for a year and placed a 'horrendous' burden on Tony. Peter couldn't understand why he had lost so much weight, why he was receiving chemotherapy, why he was suffering chronic diarrhoea; 'I needed him to know' and Tony believes that the relationship deteriorated because of this.

Tony was trying to continue to work full-time, meanwhile Peter had become doubly incontinent, 'I suppose looking back I was near breaking point.' One time when Peter was in hospital and Tony was visiting him 'I just blew my top and it forced the issue basically...I have regrets about it now, I got it off my chest in a way I didn't want to happen; it was forced on me'.

This seemed to force a number of issues. They got a carer so Tony could work 'and not to worry if he was still alive when I came home'. He had also found dealing with the incontinence very difficult - Peter would try to get to the toilet 'and you would come home to a pile of shit' quite literally. They had desperately needed help but hadn't told anyone because of not telling Peter how sick he was. After Peter knew, things went to the other extreme; 'everybody got involved that could get involved, we had commodes and incontinence nurses, this nurse and that nurse, you name it, every single day...priests, solicitors, you name it, everyone was coming'.

Tony thinks that they needed that help but his relationship with Peter did not improve: 'I have regrets because I think Peter never forgave me for it...he had so much anger and resentment...anger that I was still relatively well, that I was still going to be here after he died'. He now began to give up and persuading him to take his medication became a major battle between them: 'I was just there as a punch bag for him to hit at and I bit every single time instead of just walking away'

Tony was tempted to leave but he had made a pledge to Peter in his heart. He thinks his upbringing and his father's illness made him believe that you should stay through thick and thin, in sickness and in health. He had nightmares in which he would try to get away but was physically unable to. He wished that Peter would die. Meanwhile his own health was deteriorating; he got shingles in his face and became literally blinded by headaches. Peter was admitted to a hospice and slipped into a coma. He remained in a coma for six weeks and Tony watched him wither away.

At this point Peter's family got involved, they didn't know he was gay and the story was that he had cancer and that Tony was a friend and flatmate. They couldn't understand 'how I broke down when he died.' After the death there was hassle with Peter's family over money and they took everything away from Tony's and Peter's home.

### *Mourning Peter*

Peter's protracted death left Tony a physical and mental wreck. He went home and could feel himself 'sinking and sinking and sinking'. He began, now he had time, to focus on what he had gone through and the fact of his own HIV diagnosis. For the first 4-6 weeks he thought he was doing quite well and then things started to sink in

and 'I basically spiralled out of control'. He was on the verge of complete breakdown and his physical health was also deteriorating - his viral load was 212,000 and his CD4 count was 15.

### *Getting help*

Tony contacted the local HIV agency who organised a befriender. This at first was very helpful until the befriender made it clear that he wanted the relationship to go further. This made Tony feel very hurt and used. He also started combination therapy and anti-depressants. All of these gave him the 'kick start' he needed but by far the most helpful was starting to see a counsellor: 'she's been the one who's helped me pull myself up'.

Tony slowly recouped to become 'an HIV+ person but someone with a life...and life wasn't just about HIV and death and bereavement...and there might be some good to come out of it...I've got HIV and you just get on with it...the better you get on with it, the more positive your life becomes and that becomes less a part of your life.'

### *A stronger person*

Tony believes he is a much stronger, more positive person as a result of his experiences. His health has improved massively, his blood results are excellent and he has renewed goals and ambitions. The counsellor has helped him but he has done the work himself and feels proud that he has achieved so well.

### *Meeting Nick*

Tony had had no contact with other positive people except for at the clinic and Nick was the first HIV+ person he met. He had started going out again and dealing with whether/how to tell people his status: 'The gay community is so bloody fickle - 'oh it doesn't bother me' and then you never hear from them again'. But it was easy with Nick and they clicked immediately.

### *Contact with other HIV+ people*

Tony and Nick recently went on a holiday to Key West and Tony found the contact with other positive people very liberating, 'Their previous history and circumstances were different but it was so good to talk to people about things we's all been through...having a laugh about it.' He compares this with the lack of opportunities locally. He went to one meeting and there were four people there. One had very personal issues and was so angry about the person who infected him that in the end he left the meeting, but the other three were able to talk. Tony later met up with one of these people and found it very helpful; 'it's great to talk with someone like yourself...like an informal bond.'

### *Work and confidentiality*

Tony works in the nearby city in a financial job and has chosen not to tell most people at work because they're 'bigots'. He feels he is not strong enough to tackle people's prejudice head on and fully declare his status. He says he's quite realistic and he's not a pioneer. He knows that there would be problems if he told certain people at work.

Tony has been working in the same company for fifteen years and to a large degree has worked his way up. One of the directors is gay and after he saw Tony and Peter at an AIDS benefit when Peter was very ill, Tony Came Out to him. He says it was the

best thing he could have done as this director helped him a lot when Peter was ill. Three or four people at work know and they cover for Tony for hospital appointments etc. He took a lot of time off when Peter was ill and he feels he may have been overlooked for pay-rises, promotion etc. but now he feels he has persevered, proved himself and things have worked out for the best.

Tony says that one person in particular at work has been giving him a lot of grief, guessing that he is gay and making jibes about AIDS. Tony's response is to avoid him as much as possible and just let him get on with it. The director who is gay also keeps his private life to himself but if Tony hears any comments made about him he will defend him 'I'll say leave off and then get accused of being a shirtlifter myself. It's just so pathetic, these are men in their 40s...It sounds so petty and childish.'

Tony is still ambitious in terms of work, he feels he has clawed back to where he was in the company before Peter became ill and now he is beginning to plan ahead: 'You're always aware you've got a short life span and you want to have achieved something...If I have to finish at 40, I want to have got to where I wanted to be: I would like to be financial director', he would then feel that, despite everything, he had achieved something.

#### *Medication*

Tony feels there is a big difference to being HIV+ since the introduction of combination therapy which he feels make the virus manageable in the long-term rather than terminal. Combination therapy was being introduced just as Peter died and he feels that since then everything has gone in a more positive direction. He had cashed in all his savings and spent them but he doesn't regret that; he feels that now he and Nick are 'worrying about the things everyone else worries about.'

#### *A positive attitude*

'When you've gone through all the crap you do realise problems arise...and they can all be sorted out...when I look at what I've gone through...Having moved on, health, outlook, everything in the last 3 years, I just look forward to the next 3 years.'

Tony feels he needs to have goals in his life: 'If you're just plodding along, it's not worth living really...if it all goes wrong, I can't be any worse off than I was 4 or 5 years ago...I will gamble more with what I've got in order to get more out of it...I don't want to have any regrets basically.' He feels that his goals are achievable and, although they are harder to achieve, 'there's no stopping me really...If you know you've nothing to lose, you can't be any worse off than you were before.'

#### *Spiritual beliefs*

'I...cannot forgive God for what He's done, which suggests there must be a God for me not to forgive Him...But my viewpoint's changed completely; you're here on your own and it's up to you to make the best of your three score years and ten and then you're put in that box and forgotten about...I do think I'm a stronger person...but I don't think it's God watching over me that's made me a stronger person. I think...you're tested and you either cope with it or you don't...I just can't see why people should suffer like they do'.



### *HIV within the relationship*

Tony feels that he and Nick are 'as near compatible as you can get' and that is in part because they are both positive. He feels he has been able to give Nick the benefit of his accumulated experience of the virus and it is very important to him that Nick takes combination therapy and looks after himself.

### *Health now*

Tony struggles with a congenital problem with the veins in his legs which, together with lypodystrophy, has caused some wasting in his legs and also his face. Nick has tried everything he can think of to try to improve this but he is still extremely self-conscious and anxious about his appearance. He finds this very debilitating and asked his doctor for surgery, which would reverse the problem, only to be told that there were insufficient funds and that he was simply being vain:

'They don't understand how much improvement in self-confidence it would be...it's the image of AIDS, the image I have of Peter...that's one image I would like to wipe out of my memory...I don't think I ever will'. He also hates the lack of control over it; there seems to be nothing he can do reverse the process, although he feels he will gradually come to terms with it.

This, however, seems symbolic of how it is for Tony living with HIV:

'The tide's coming in and you've built a hole and you don't want the sea to come in the hole and you're plugging the different parts of the defences...the drugs saved a hell of a lot of our lives, but you have to pay for it in another way'.

### *HIV in daily life*

'I've spent a third of my life with HIV...I can't remember what life was like before it'. There are always restrictions such as the tablets, difficulties with travel, fatigue, hospital visits, anxieties about blood results and still a shortened life expectancy. But Tony does feel that, although his HIV needs to be monitored and is potentially life threatening, while it is manageable he can get on with his life.

## **Participant 7 - Gordon**

Gordon is a 36 year old man who was born and has lived all his life in the east end of London. He was diagnosed at age 21 in 1985 and his partner died of an AIDS related illness in 1992. Gordon worked for many years in the theatre industry and has been actively involved in AIDS Service organisations and organisations for gay men. He now is involved in various voluntary and community projects and lives near to his partner, Steve, with whom he shares care of their dog.

### *Coming Out*

When he was 10 or 11, Gordon heard Anna Rayburn giving out Gay Switchboard's number. He 'phoned up and was silent but he says at least he knew that they were there 'I was very certain by 10 or 11 I was different', he used to go by himself to Museums and Art Galleries, by 15 he knew that he was gay and was able to 'phone Switchboard again and talk. The 'wonders of the red bus Rovers' gave him the freedom to go to a gay teenage youth group whilst his mother thought he was at a Church Youth Club; 'I had on the suit that was bought for my confirmation, a brown tweed suit and tweedy tie'. Eventually his family found out and the Parish priest (who was also gay) was very supportive. Gordon's father however was 'vile' - he later Came Out as gay himself but remained very closeted and only the family knew, 'No one else does, apart from all my friends - my funeral's going to be dreadful because all my friends know my dad's gay!'

In his earlier years his only role model was Quentin Crisp, 'the queen', but that was quite positive in that Quentin was unafraid and didn't worry about anything and so Gordon adopted that attitude. 'Some vile things happened, I got cornered in a 'phone box and spat at and beaten up but I was Out and it was over and it was done.'

### *Family*

Gordon's mother had a brain tumour removed in 1965. She has a hole in her skull and some brain damage which means that she can be forgetful, say things which may be inappropriate and suffers from mood swings. 'Eventually she will peg it and join the angels...I love her very much'. When she got married she was told by his father's mother that his father was 'very special' but 'I didn't click what she meant for 30 years.'

Gordon was largely brought up by his maternal grandmother and he has one sister, both of whom he describes as 'brilliant, wonderful'.

### *Spirituality*

Although his mother was and is a very devout Catholic, the family was politically socialist and going to Church was always regarded as a matter of personal conscience 'Even now I'm a sociological Christian but not a religious one...I believe in society and try to be responsible about the world but I am largely rationalist.' He hopes that there is something more than this life but he cannot adhere to one particular doctrine; he simply feels that we should value the life that we have, try to make the most of it and try not to hurt people.

### *Living in the East End*

Gordon was born in Whitechapel and except for three years in Ilford 'where the East End gets posh' and which he hated he has lived in Tower Hamlets all his life. When he was looking for his current flat, the council offered him a place 'in a neo-Nazi bit of Poplar' where another gay man with AIDS had been firebombed and forced out. The area has pockets which are safe and areas which are not and Poplar is an area where a National Front candidate was elected. The block opposite had BNP graffiti which was painted out twice a week. Gordon describes it as 'an area of extreme alienation which manifests itself as homophobia and racism and sexism. It's more to do with disempowerment and alienation and people feeling like they don't have any kind of control in their lives so they blame the Bangladeshis or the poofs in an attempt to get some kind of control.'

Gordon is happy with his current flat which is comfortable, opposite a park and his partner's flat is only 10 minute's walk away:

'It's where I've always lived, it's where my roots are, walking through...the Park and visiting where my aunt's shop used to be and my grandmother's flat's over there...I feel safe and comfortable.'

### *Diagnosis*

Gordon's late partner, John, had had some bad dental treatment done in the early 1980s. When he tried to get it rectified the new dentist found he had swollen glands and refused to treat him unless he had an HIV test. He went to St Mary's on friends' recommendations and tested HTLV III positive 'and that was the start of it all'. He and John never worried too much about possible routes of infection 'we were never monogamous and it was never that kind of issue'. John 'phoned Gordon at work to tell him the test result and Gordon knew he would also be positive.

### *Initial support*

John and Gordon were sent to see a psychologist and Gordon describes the resulting change in their perspective as 'amazing': 'We went in to see him thinking that we were going to die, we came out thinking what are we going to do with our lives...John did his accountancy qualifications, I got on with a life in theatre...we got on with our lives rather than feeling sorry for ourselves and that's actually stayed with me.'

Gordon doesn't like 'the drop-in centre, symptom-swapping victim mentality' which he found to be particularly prevalent in the mid to late '80s. His current 'very eccentric' homeopath believes that his survival is due to his motivation, to the fact that he keeps doing things, 'I have lived 5 times longer than the maximum predicted; I was told I had about three years'.

### *Work*

Gordon's work in the theatre was enormously important to him and at times, for example after John died, it was a way of keeping going. 'I was a bit of an obsessive workaholic, but it was wonderful, it was a really good thing'

Gordon found working at the theatre increasingly difficult because of the muscle damage in his legs caused by the AZT. He decided to stop work when he felt his health beginning to fail because he was concerned that he would no longer be able to

operate reliably; he did a job where he was not prepared to ask people to do things that he wasn't able to do himself but the AZT 'completely fucked up my legs and it was really horrible...giving up work was a hideous decision'. He saw the Union and was paid off quite comfortably 'They were very reasonable; everyone was really nice.'

He now wonders if he regrets being so up front about why he was leaving as it might have made it more difficult to go back into the field again and he clearly missed and still misses it, 'It was really really good and I resented leaving it and I did go through a grieving process...but it's gone and I'm doing different things now...It was part of my life, it was exciting, it was wonderful. I expected I would be dead within three years of leaving'. He also points out that, although the Benefits are good, when you are on them long-term, it is hard to afford one-off expenses.

#### *Alternatives to work/getting back into work*

Since giving up work in the theatre, Gordon has got involved in a number of community projects. He compares himself with other positive friends 'who do valium or dope and vegetate...I can't do that, life is too short'. He is currently involved in a neighbour mediation scheme and is starting to get involved also in victim mediation which he hopes may lead eventually to paid work. In the meantime, such work all forms part of 'being part of a community'. He has also been a volunteer for years in a leading organisation providing support to gay men and lesbians 'It's a part of my life...I believe passionately in what it does...again it's being part of a community, it's something I participate in.'

#### *Health*

Gordon goes regularly to a gym for men with HIV which is 'brilliant, truly wonderful'. It is a social occasion and it has enabled him to become a lot stronger, repairing some of the muscle damage in his legs caused by AZT'. It is affordable and while 'not officially a gay space, it...seems like it is sometimes.'

#### *AZT*

John and Gordon were almost like twins; they were born ten days apart in June 1964, both from the East End and both looked very much alike. 'We were very very close from age 19 till when he died at 28'. They both started on the AZT trial but Gordon 'chickened out' when his leg muscles started to go. John started to get anaemic but he was fine again after a blood transfusion and after the dose of AZT was dramatically cut. However, when it was time for him to go back for another transfusion he had become very weak and when Gordon tried to lift him out of the bath they both fell. The ambulance journey across London to the hospital took six hours. At 9.30pm John sent Gordon home to get some rest and something to eat, at 1am he had a seizure, the next morning the hospital 'phoned to say he was critically ill and he died that evening.

#### *John's death*

Telling John's parents about his illness 'was the most difficult thing I've ever done in my life'. They are very ordinary, working class, 'Sun readers' and when Gordon told them, with the doctor sitting in the room, his mother got very upset and his father got aggressive. 'I don't know how I did it'. They left but Gordon had later to ring them to ask permission for a post mortem.

John died intestate. In the ambulance on the way to the hospital he had agreed to make a will when he got out. Despite Gordon having known them well for many years and despite having been 10 years with John 'his family were completely vile'. Gordon asked that John's estate should be split between his two younger brothers 'that John bunked off school to bring up because his mother was always on the vodka and orange squash' but his wishes were not taken into account. He had to get a solicitor's letter to claim the possessions in the flat which were owned in common, not forming part of John's estate. He was angry with John's mother and brothers because they were people he loved, but acting on that anger wouldn't have achieved anything.

'I had nine and a half years that were good with John and I loved him and that's what's important; what happened afterwards, after he died is an irrelevance...yes it was upsetting at the time, I have never been more hurt in my life; it was awful, but it was nothing to do with him.'

As a direct result of this experience, Gordon spearheaded a campaign to raise awareness amongst lesbians and gay men over the importance of writing wills. 'I always find a way of channelling my anger and doing something constructive with it'

Gordon quotes the Sondheim song 'Not a Day Goes By' - 'I think of him every day. Not in a nasty way...it's just he was part of my life for near enough 10 years and I still miss him.'

Gordon is reflective about the fact that John's death was a direct result of anaemia caused by AZT 'it's desperately sad but we've learnt from it and that's as much as we can ask'. He feels that AZT probably did prolong lives (although not as dramatically as septrin) but no one had any idea about dosage. It was terribly sad but he doesn't feel that anyone was to blame. 'I don't believe that these people who have spent year upon year of their lives training and studying are doing it with malicious intent' He also points out that last year was the first year since the early '80s that he didn't go to a funeral; 'in the context of what was happening in 1992, John's death wasn't unusual'. John and he met at a lesbian and gay youth group in the interval between their 19<sup>th</sup> birthdays 'of that generation I'm one of three surviving men, the rest are dead'. Now with combination therapy and the fact that most people have gone it is difficult to imagine how much it was happening. The only thing that was unusual about John was that he died so quickly.

### *Surviving*

Gordon has made new and different friends but he had a 'chosen family' of friends and those relationships cannot be replaced. He makes an analogy with war and with his grandmother who will 'drag out photographs of going hop-picking and all the people in her photos are now dead.'

He remembers a Far Side cartoon of a dinosaur in a cave settlement with the sign 'Sorry, extinct' and he has felt like that. In the mid '90s there was a backlash against the gay men from an 'earlier' generation and although he does not think there is much to be gained by dwelling too much on the past, there is a sense of a generation gone. He has one positive close friend now whereas in 1985 he had probably 10 or 15.

### *Coping*

Gordon quotes Engels who said 'Don't mourn, organise!' and 'Living is the best revenge'...'organisation I believe in. I'm a joiner - I get involved and do things...I believe in communities.'

He used to control his time for grieving, making time on Sundays when he would play music and cry. On the other hand he is also clear that it is not all consuming: 'It isn't something I allow to be hugely significant in my life; in terms of the things that identify what I am it's a long way down the list.'

Gordon says that now he tends to get depressed on anniversaries etc. and he is not ashamed at those times of having a cry and getting it out of his system. On the whole, however, if he feels that if there are negative things in his life he will change them. It is important for him to feel that he is in control of his life. Unlike some of his friends he does not feel the need to blur reality with drugs.

### *Health*

Gordon describes himself as having been 'boringly stable for a long time' and the graph of his blood results is almost a straight line with his CD4 count at 200 and his Viral Load at 2,000 even though he has been on the same combination of drugs for six years; unless there is a change in his results he sees no reason to change his treatment.

After John's death Gordon changed clinics, largely for easier access and because people he had known and loved had died in the other hospital. After an unfortunate experience in one clinic he found a clinic on an easy bus route where he is happy with his treatment and he has been going there for six years.

Gordon's partner has a disability and Gordon compares treatment for people with HIV/AIDS very favourably in comparison to the treatment of patients with other conditions.

### *Social Services and voluntary organisations*

Gordon's experience of social services provision has also been very favourable. An occupational therapist helped him with his housing and he has a Home Help who is 'wonderful...brilliant, I like her a lot'. His benefits were sorted out at 'just the right time' through THT.

In terms of voluntary organisations, Gordon describes himself as an 'old hack'. At the age of 16 he took the first age of consent case to the European Court and he knows and is well known in the primary HIV and gay men's organisations in London. He says that consequently it is easy for him to access help and advice when he needs it because he knows the system and he knows individuals within these organisations. He is scathing, however, about some of the organisations, one of which he describes as 'full of people who'd been diagnosed five minutes being completely pathetic and feeling sorry for themselves; he himself finds more support through friends rather than structured groups.'

### *Complementary therapy*

Gordon is sceptical about the credentials of some complementary therapies but saw a homeopath regularly for 5-6 years which he found very useful at the time and would go back to if and when necessary.

### *Gay community*

Gordon describes the urban gay community as 'a series of communities bound together by friendship and common interest' which might be bars, the church, lesbian motherhood, geographical proximity etc. 'In the city there are lots and lots of groups and each of us is in lots of groups and our relationship to each group is very different'. Gordon strongly believes in community as a concept but it is 'a nail in jelly' and not easily quantified although he believes that communities need to have a common interest and friendship to form and cohere.

In his 20s Gordon says that his whole life was 'sex and drugs and disco'; he worked at a gay nightclub and his whole life was gay, either as work or as a punter but it was only healthy for a short time and he feels it was 'a very narrow and bitchy view of the world' with a lot of backstabbing and infighting.

### *Daily life*

Gordon goes to the gym three times a week in the morning, he will shop etc. in the afternoon, work on his computer and cook in the evening. Apart from that he doesn't have a fixed routine but his diary gets booked up and he stays busy with his community work. He keeps the weekend free to spend time with the dog, relax and will often go to the theatre or opera with his partner.

### *Relationship*

Gordon has been in a relationship with Steve for 6 years. Steve is negative but also has a progressive disability 'which has led to a whole series of discussions to do with me not feeling so sorry for myself'. Steve is very down to earth and grounded, 'It works'. Gordon is clear that, if it no longer worked, he would end the relationship 'but I can't see us splitting up and I sincerely hope we'll be together for a long time'.

### *The future*

Gordon is planning to do an Open University degree and he hopes that his voluntary community work will eventually lead to paid employment. He tends to have one big thing to look forward to which is concrete and 'woolly plans' for the next five years. 'In five years time I'll be 41 and I will have been positive for 20 years. I didn't think I'd see 30...now 40's a realistic prospect.'

Gordon says again that for him 'living is the best revenge...There is no alternative...If you can live life constructively, do things for others, make the world a nicer place to live in for yourself and yourself, at least you will have done something'. He wants to do things that are part of the wider world, 'everything I do tends to be part of something a bit wider'.

Gordon describes himself as 'supporting, making things work, making things pretty' - like a swan, full of grace and elegance on top and 'working like hell underneath!'

'I just keep on doing things because the alternative is really dull...generally things are good and I'm reasonably happy.'



## **Participant 8 - Stefan**

Stefan is a 40 year old man who was born in Germany in 1959. He moved to England in 1991 where he Came Out as gay. He was diagnosed in 1997 and now lives in London with his partner Gareth (participant 16) and works in the city. He is on combination therapy and his health is good.

### *Diagnosis*

Stefan met Gareth in March 1997 and in May Gareth was hospitalised with a sero-conversion illness. After Gareth was tested positive, Stefan also tested positive and in retrospect realises he was probably infected in 1995. At the time of his diagnosis his blood results were not good so he started treatment immediately with drugs which were still on trial. Since November 1995 his viral load has been undetectable.

### *Coping*

Stefan chats on the internet with someone who is very angry with his boyfriend for infecting him but he doesn't feel it's useful to blame anybody else for your problems 'It's a tough game, it just happened. I can't do much about it but I can make the best of it'. He compares HIV about which he feels he holds some measure of responsibility to other things that can happen which feel to him to be totally someone else's fault, about which he tends to feel much more angry.

Stefan is a virgo and feels this might be why he is practical and efficient and this helps him to cope, particularly with regard to adhering to his drug regime.

### *Medical Treatment*

Stefan has been going to the clinic once a month because he has been part of a trial. This has meant that he knows people's faces and one of the doctors recognised him in the street the other day. He appreciates the familiarity this regular contact gives him.

### *Voluntary organisations*

Stefan was involved in a gay men's organisation but says that it felt like the gay community; he was always rather on the outside. He also feels that his priorities have shifted now he is in a relationship and has less free time.

### *The gay scene*

Stefan describes the scene as 'very superficial' full of young people with model attributes; if you don't fit in you are completely ignored. He prefers to spend his time at home with Gareth - 'a boring couple's house life, the sofa, tele, tea'. When he was single he went out more often but preferred more local pubs to Soho; 'people are more likely to take you for what you are, rather than your bank balance, looks, age...you're not fitting my profile, bugger off.'

Stefan says that Gareth is even more uncomfortable on the gay scene because he hates people looking at him. Since they have been together they have gone out less and Stefan is very happy staying at home and relaxing; 'now the urge has gone, it's nice at home.'

### *Community/home*

Stefan and Gareth have recently moved house partly to be somewhere larger and partly to live in a house rather than a flat where they have more freedom. The local shops are good although they moved for the house rather than the area, although they didn't want to live in a 'dodgy' area. They have a car so they are able to travel easily.

### *Coming Out*

Stefan was born in a small town of 40,000, then when he was 6 his parents moved to a town of 70,000. When he was 15 they moved to a village with a population of 250 where the nearest town which had a population of 40,000 was 10 miles away. It was very close to the East German border and was 'dead-end quiet'. On the other hand, it was the place that Prince Albert had come from so, although it was a dead end, tourism was able to keep it alive in a cultural sense. However, the last bus home was at 8pm so it wasn't until Stefan got a driving licence that he had a measure of independence.

After leaving home Stefan lived with his girlfriend but would often spend weekends with his parents. In 1991, he and his girlfriend decided to move abroad and chose England because they were both able to work here and could both speak English. It was only after he had moved to England that Stefan began to accept himself as gay -'It took a long time to accept who I am and what I am'. He moved to England first and was then joined by his girlfriend. The relationship wasn't working and the move didn't revitalise it and Stefan started going to gay bars.

Stefan describes the first time he went into a gay bar: 'You are leaving the world you know and you're going into something where you've no clue how the whole thing works'. For years he would get butterflies if he went into a gay place for the first time. Now, however, it feels like the most normal thing in the world, 'like going into the supermarket.'

Stefan thinks that one of the reasons it took so long and a move abroad to Come Out is that his mother is a very strong-minded person. He has never actually told her that he is gay: 'It's something we don't talk about but everybody knows'. He doesn't feel he has the strength to tell her as she is so unpredictable.

### *Living in London*

Stefan works in the city in a financial job. A couple of colleagues know he is gay but otherwise 'I don't know if they suspect anything, we don't talk about it; I don't say anything, they don't say anything'. If he was asked directly if he was gay he would either answer 'yes' or would ignore the question, depending on the individual. He says that some people might criticise him for wasting his life by being in the closet at work 'but you can't chose your colleagues' and it seems to be the best way of making work life manageable.

Stefan regards his HIV status as different and would be very careful *not* to reveal that at work. On the other hand, he did disclose his status when they needed a bigger mortgage and it was only because he already had life cover from an old policy in Germany that they were able to manage. Stefan said this cost him quite a few sleepless nights. On the other hand, he has subsequently lied on forms about his sexuality and his status and that has also made him feel very uncomfortable.

### *Health*

Stefan feels that in recent years if anything his health has improved because Gareth cooks and makes sure he eats appropriately.

### *Spiritual beliefs*

Stefan's parents were not very religious. His father used to go to Church at Christmas and take Stefan with him to leave his mum free in the kitchen but his mother doesn't believe in any form of life after death. Stefan had more contact with the Lutheran church because he sings and in England he used to attend the American Lutheran Church.

He is uncertain about the existence of God; he does not agree with much of the Church's teaching, for example about gay issues. He regards the Old Testament God as a frightening, punishing figure and the New Testament God as more forgiving. He thinks that some religions, for example Buddhism and Hinduism, are more advanced in that they are about what you make of your life, whereas the Christian Church leads you by the hand and tells you what to think.

Stefan cites a book which he has found particularly inspiring called *The Art of Loving* by Erich Fromm in which Fromm suggests that loving someone is less a feeling than an art that one can learn.

### *The future*

Stefan has adopted Gareth's attitude which is one of living for now rather than worrying about the future. He hopes the pills will work until he retires because it would be nice to see the fruits of his labours, 'but it is not down to me to decide' and anyway there are many uncertainties about the future, not just HIV. He and Gareth have thought that when they are older they may want to move out of London where the pace of life is a bit slower; in London 'You're just walking yourself through, hoping not to bump into too many people...hoping the queue at the checkout is not too long'. Although he finds the anonymity of London attractive, he feels that he may appreciate a closer community in later life.

### *Being gay*

Stefan is happy being gay; he feels it gives him access to another world: 'I'm living in the straight world anyway to start with, what's close around me, or what's outside the front door, but on the other side there's also the gay world which has also got things to offer'.

### *Daily life*

Stefan gets up at 7.30 and leaves for work at 8.00. He catches the train to and from work and in the evening he has dinner, watches some television and goes to bed. At the weekend he doesn't work - 'thank God' - and is clear that he wouldn't allow work to spill over into his free time. His hobby is classical music and singing and he sees this as a welcome contrast to work which probably makes him better at work. He feels that, whereas other people may use alcohol, singing and music help him to calm down.

## **Participant 9 - Paolo**

Paolo is a 31 year old Italian man. He was born in Tuscany and came to London 6 years ago to do an English course. He had been manager of two tea rooms in Italy and, although he has decided he will never go back, he doesn't necessarily see himself as settled: 'I don't see any place in this world for ever'. He was diagnosed in March 1998 and the positive result was a 'very big shock'. He currently works part-time in a straight bar in Soho but is contemplating a change in career. He lives on his own in a flat in London.

### *Growing up*

Paolo grew up in Italy but his mother was Sicilian. He says that Sicily has a different culture from Italy; it is expected that people live with their parents until they get married and then have children and sons grow up to do the same job as their fathers, Paolo says 'I was against all of this'.

Paolo had a relationship with four girls and one woman but down at the beach it was the boys he would be looking at and he tended to be more friends with his girlfriends. He had had quick sexual relationships with other boys but no more than he believes most boys experience as they are growing up. When he was 19 he had a relationship with a woman of 34 who was sexually sophisticated but Paolo still wanted more.

Paolo says that 'I still have the pain of what happened to me'. He describes himself as born into a fascist family; the culture of his parents was very strong 'like they're washing your brain'. Finally at 19 Paolo came to a realisation that he was gay. Both his sisters know. His younger sister found it hard as she was the butt of jokes about her brother at school but now she lives in London and she and Paolo are very close. Paolo left home at age 21 against his mother's wishes; she had said that if he left home she would never have him in the house again, but in spite of this they now have a good relationship. He has never explicitly told her that he is gay, he is sure she knows but doesn't really want to know. Paolo says that sex is a taboo subject anyway so it's not that difficult: 'Today I would have to do a double with a knife because I'm gay and HIV+, why give her pain?'

### *Italian Culture*

Paolo describes Italian men as leading a double life. In the cities there is one area where the men can show off and another area where they can have a private life which will often involve sex with other men. When Paolo lived in Rome he was the manager of a café and he found the gay life in Rome very exciting. He would see customers in the café whom he had met in the gay bars and would try to talk to them but they would blank him and they stopped coming to his café. He also found that men would not come home with him when they found out he did not live in one of the posher areas of the city. Paolo found these double standards very difficult: 'I've got just one face, I'm happy with that'.

### *London Culture*

In contrast Paolo finds the culture in London much more comfortable although he does not personally describe Soho, where he works as a gay community: 'I think there is just a little corner where someone gives to himself a space'. He describes the club in

which he works as quite homophobic but since he has been working there he has made a lot of light hearted jokes with the straight men and he feels attitudes have changed. He feels that straight people are scared of gay people and he feels he helps to protect himself by making lots of jokes about it. He has done this at work and won people's acceptance: 'I make space in my way'.

Sometimes Paolo doesn't feel comfortable when he goes to a straight place but he won't let homophobic attitudes affect what he does and where he goes; 'The last word is always mine'. He has had some difficulties in the flats where he lives, such as mothers keeping their children away from him or people making homophobic jokes or hurling abuse but Paolo says 'They don't really touch me'. Sometimes when people say things to him he pretends he doesn't understand the language; they want a reaction but Paolo says he doesn't want to make anything happen as he has to live with these people.

Paolo finds people's attitudes in London very cold; in Italy people would greet each other in the street but in London they ignore each other. Paolo lives in a council block which forms part of an estate. He would like to move as he feels that the diverse groups of people living so close to one another does create difficulties. For example his neighbour in the flat above has flooded his place and caused damage which he has refused to pay for. When Paolo challenges him he calls him a 'poof'. There is another gay man in the block who is known to sell sex and the elderly neighbours who Paolo helps with their shopping will talk about this 'poof' not realising that Paolo also is gay.

#### *Diagnosis*

Paolo's boyfriend and he used to practice safer sex but, after one occasion of having unsafe sex his boyfriend pressurised him each time they had sex not to use condoms. Paolo felt something was wrong and decided to get tested. The positive result was a great shock as they had only had unsafe sex 2 or 3 times. He told his partner to go to the clinic but he started to 'run away' and in a month came back with another man: 'He lie to me, he knows he's positive, maybe scared to test. When I try to talk about HIV he puts up a wall. I don't think he wanted to infect me but I think he knows what he did'.

After his diagnosis and the end of his relationship, Paolo became very depressed. He had no sex for a year and then when he started to have sex again he was very anxious. He compares his attitude with other positive men in London who think that it is the negative partner's responsibility to protect themselves and whose attitude is 'Fuck the virus, fuck everything'. He, however, felt like he was in the film 'Alien'; 'I felt like I had something inside' and he was very anxious about infecting someone else. He felt empty, scared, shocked, too different from 'normal people.'

#### *A more positive attitude*

Paolo says that much of his depression and anxiety has now lifted and he has learnt to get on with life 'The positive...feeling of life, amplified joy to life. Every day special because before I was scared to die'.

When I asked him about what the good things were in his life, Paolo replied, 'Oh my God, I don't know...no, no, no...I feel good every day, every day is a special day: love, plants, animals, all humans...everyone has got an energy, everybody is the same

and not the same; we can learn from anyone...I'm happy for everything, stupid things...'

'...Whatever happens to me in my life is something good-bad...we can find in the negative moment something positive' and Paolo believes that we can very much make this happen ourselves.

Paolo has had to radically change his attitude to life in terms of his plans: 'I don't dream any more, I don't have my dream any more. I broke my dream with a hammer'. His dream had been to open a café but now that wouldn't be enough for him. His dream now is to have his life rich and full.

#### *Work*

Paolo is a waiter in a bar in Soho, but he would like a change of job because he finds the night work tiring, although it is better since he went part-time. His brain likes the work and he likes the buzz of working under pressure but his body is not as strong as before. He has worked unsociable hours in the catering industry for 15 years and he misses things which other people take for granted like watching TV with friends 'Lots of people would think it was boring but right now I think it's amazing.'

#### *Community*

Paolo describes his community in terms of the different sounds he can hear through the window of his flat; Saturdays, Sundays and weekdays all have different sounds, different 'languages; 'People different, different days and different times of day'.

#### *Health*

Paolo says his health has fluctuated since his diagnosis. When his doctor first recommended he started treatment, 'I throw a fit on the ground. No! I don't want to start now!' He is also Hepatitis C positive and his liver function tests were poor so that was also a concern. Paolo was very anxious that he might forget his tablets if he started HAART.

Since going part-time Paolo's health has improved dramatically his CD4 count rising from 220 to 600 and his viral load falling from 180,000 to 6,000 copies; 'a good quality of life can improve this illness for sure'

He has learnt to tune into the language of his own body; he is more aware when he needs sleep, food, what sort of food etc. He looks and feels very well and sometimes he finds that difficult when his blood results are poor. He has decided to wait to start treatment until his blood results are very poor. At the moment 'I never think I'm HIV+, you'd just make it worse...no, I feel like before, full of energy, full of life.'

#### *Medical support*

Paolo describes his doctor as 'lovely' although at first he was very mistrustful of her. When she advised him to start treatment he was 'very horrible with her and she was so sweet'. The journey to his clinic takes about an hour but he would not want to change doctors because he has such a good relationship with her: 'I love my doctor...I will stick with her...I treat her badly and she's cool.'

Paolo is less impressed with his GP. His consultant persuaded him to go to his GP's with more minor concerns but they have not been helpful 'You've got five minutes, take this, take that...maybe I've got paranoia, I'm not in treatment.'

### *Other Support*

One source of support for Paolo has been from the psychologist at his HIV Clinic. When he first went to see her he could only see the negative aspects of his diagnosis. He describes going to see her as a 'wake-up call':

'Life is beautiful. If you want to live, you find the way to be...this life is a kind of movie, you decide what you want to be, if you want to be the sad one, the victim, you decide'.

He has started going to see her again and is working to 'make myself again upside, have the right position, try to improve my life in all aspects. Certain aspects are fine but other aspects are so crap'. He feels that this work in itself takes his energy and he has to be patient with himself. 'I'm very easy but complicated'.

Paolo praises a London-based voluntary organisation which was very helpful when he was first diagnosed but unfortunately has recently closed. He didn't go regularly but he liked the fact that it was there if he needed it. He has now joined another organisation which he hopes will fulfil the same role. He does not always find it useful or easy to talk about his experiences:

'To meet people and say all the things; sometimes I don't want to think about the past, think of the present or the future. Maybe there are funny memories or a song that make the connection. I don't want to hold it. I don't want to say everything again and explain myself.'

Paolo also used to be a volunteer for a gay men's organisation but he left when he felt he was doing work which paid staff should be doing.

### *Relationships*

Paolo would like again to have a partner but is also very protective of his space and privacy, 'I don't want to sacrifice any more, I'm scared to sacrifice for nothing'. He believes that gay relationships are harder to maintain because children will keep a relationship alive. Although he would like another relationship in the meantime he enjoys flirting. He is also selective about his friends and has an honest straightforward relationship with them. He tries to cut down on stress and does this partly by only spending time with people he regards as real friends.

### *Spiritual beliefs*

Paolo is a Catholic because his family are Catholic but he describes himself as religious in his own way. He believes in God, a big energy, but in a way that is personal to him. He believes that you create your own reality and anything which happens has the potential to be something positive or something negative. One of the important things in Paolo's life is music.:

'Music is feeling...everything is music...animals, humans...music is like perfume...it makes me feel god, spiritual, relaxed'.

## **Participant 10 - Jon**

Jon is a 32 year old man who was born and his lived all his life in London, except for a period away at University. Articulate and well informed, he now works for a gay men's HIV organisation in a high profile job. He was diagnosed in 1998 as HIV+ but so far has been asymptomatic. He lives with his flatmate in a flat he owns in south London.

### *Growing up*

Jon places a retrospective homoerotic interpretation on a childhood dream of being confronted by a big hairy man and all his clothes disappearing. He grew up in a middle class inner London household and, having a middle class accent, liking books and not liking sport, he was called a 'poof' at school. At 11 he was sexually assaulted by a stranger. He is certain that this incident didn't make him gay but he wonders if it led him to question his sexuality at an earlier age.

Jon describes the year he was eleven as a bad year. He was sexually assaulted, he started at secondary school which was 'a nightmare' and he was displaced as the youngest in the family by a new baby sister. From this point he began to be independent of his parents and by the age of 15 he was very independent.

His early image of a gay man was 'Jon Inman or a pervert in a flasher mac, I didn't want to be either!' so he dated girls from age 13. He had a good social network, especially with the girls at a neighbouring school and dated many different girls. At 15 he had a sexual relationship with a 17 year old girl. Now he finds this shocking but at the time it felt very right. She told him that she was bisexual 'and I said 'me too''.

When she went on holiday with a girl she was also sleeping with and Jon's parents were away, he bought Time Out and looked at the gay listings. He didn't understand half the terminology but he decided he would go to Heaven. He arrived at about 9.30 when it hadn't even opened. The music was high energy 'it was strange, exotic and extraordinary...so sexual...very new and different, very exciting. He saw gay men with moustaches, check shirts - a very macho image 'which was great because it was very masculine and they looked very proud so they weren't at all the Jon Inman or the flasher mac perverts.'

Jon knew he had a mission, which was to have sex with a man. He had thought no-one would pay him any attention because he was too young but within 10 minutes an American man was talking to him. They went back to his hotel and had sex.

'I remember very clearly sitting by the window kissing - he had a moustache. We had sex a couple of times. He fucked me, but I don't remember it hurting. I guess I was so in to whatever was happening that it all seemed fine...and that was that, and that was how I felt about it. I thought - OK, I've done my bisexual thing now - I'll go back to women...I had ticked a box and I could move on.'

Jon realises that living in London gave him a whole range of possibilities: 'All I had to do was decide that it was what I wanted to do.' On the other hand he felt conflicted



about identifying as bisexual; there was a lot of prejudice but there was also David Bowie: 'He was very cool and his sexuality was ambiguous, so being gay wasn't cool but being bisexual was sort of acceptable.'

Between the ages of 15 and 20-21 Jon describes himself as 'a bit of a goth...I tried to neuter myself...I didn't want to be male or female, I just wanted to be a sexless blob...It was quite an extreme look but it was also...quite a defensive shell for me and I think it was a lot about my sexuality which I was coming to terms with, and when I did come to terms with my sexuality...I then started to shed that image'.

Jon points out the lack of positive gay role models compared with today, 'but David Bowie helped...and *Brideshead Revisited* helped...I remember saying...well I'm not gay but I would sleep with David Bowie and that was something I could say to my male friends at school'. By the time Jon was in the sixth form, although he was still regarded as odd by his peers, 'I was starting to take control of my oddness and celebrate it'. He was still having relationships with women, partly because women found him very attractive, but he was beginning to feel that he was more attracted to men.

He fell in love with another man; his girlfriend's ex-boyfriend, when he was 17:

'I kind of decided I would like to have sex with this person, even though I'd never met him...I kind of fell in love with him just hearing her talking about him and then a really odd thing happened because I met him and it all came true. We had this...instant connection that we were both too scared to talk about, and he wrote me a letter that was very cautious...and I wrote back...nudging it forward. Then we were at some party and he said 'I want to show you my diary' and he had written in his diary about me and that was when our affair started...He lived in Richmond and I would go and hang out with this Richmond set and I would "miss the last bus home" and he would say "Oh you can stay at mine" and we would set out the spare bed on the floor, go to bed, turn the lights out, and then his hand would come down and touch me and that would be the signal. I would get into bed with him and we would have sex and then I'd get back into the other bed. It was all very loving...and in private times we would kiss and whatever, but it was completely secret, and I think he was very conflicted...he wanted to end it but he couldn't bring himself to say so...I was very confused...Eventually it absolutely was over, even though he never said it was over...I was really devastated...and that's when I told my mother because I was so unhappy, a 17 year old crushed in love, sighing on every doorstep.'

Jon Came Out to his parents separately. On the night he told his mother, he had asked her not to tell his father but she said to him 'You might have AIDS for all I know' in front of his father. Jon was very angry at the time, but says that was the only moment when she was not OK: 'She just had a little bit of hurt and anger and got rid of it in one evening...Secretly she was pleased, because she thought there would never be another woman who would mean more to me than her...And I think my mum really enjoys worrying...she's had a fair amount of mileage in the fact she's got a gay son.'

Jon's father is an alcoholic and was very absent from his childhood. In hindsight he feels that his mother poisoned her children's minds against him; he can see now that his mother is not an easy person to live with. His father found out when Jon brought

his partner home from University in the holidays. There was a spare bed set up but was not being used and Jon's father walked into the bedroom. It was all extremely embarrassing but not long after his father rang him at college and was very affirming and caring (his mother later implied that he was so drunk that he wasn't aware of even making the 'phone call).

Jon describes his parents as 'small 'l' liberal and feels he had a very easy Coming Out process. He and his older sister cannot remember when he told her, she says that at the time she was so uninterested in her brother that she wouldn't have paid any attention! He waited until his younger sister was 15 as he was concerned she would be picked on at school. He describes their relationship now as very close.

### *University*

Jon places starting university within a political context. It was 1986 when there was the first Government Campaign about AIDS and the start of Section 28 which 'was the thing which pushed me out of the closet and made me affirm my sexuality...as we were being actively attacked I felt I had to declare my colours'. He started seeing a man in the year above who was politically involved. Jon says he was very strident about his sexuality, especially with his parents, but he defends himself by saying that there is always an assumption that everyone is heterosexual.

Jon was sexually assaulted for a second time whilst he was at university.

Jon describes a change of image at this time:

I was coming out of my Goth period, shedding my shell...and I did this in a rather extreme fashion, I actually posed nude for a gay porn mag...They were quite Goth-y...I was frowning in all of them, I was wearing clothes for most of them...[but] I was starting to come to terms with the fact that perhaps I wasn't ugly and I wasn't fat and that perhaps I could be attractive. It was almost like when I went to Heaven - 'OK, let's see what I can do about this'.

This happened at the time when the very powerful university Gaysoc were taking an anti-porn line in co-operation with the current feminist debate. Jon believes that gay porn, being produced by gay men for gay men represents a completely different power relationship. The result was that he became 'Public Enemy Number One' and was asked to leave the Gay Soc. Jon says that he did it to prove to himself that he could be attractive and because it paid good money 'but I did seriously consider doing it again to say I'm not going to be crushed'.

### *Drama College*

Jon found Drama college very exciting but very tiring - 12 hour days and one and a half hour's travel. The only sex he had time for was occasionally on a Saturday night or on Clapham Common which was on his way home. But really he wanted a relationship.

### *The love of my life*

When Jon met Ben there was an instant attraction: 'I've no idea how we managed to survive that first month because I think I was completely obliterated by how devastatingly sexy and charming...he was'

Early in the relationship Jon decided that Ben had either been bereaved or he was HIV+ and after about a month Ben told him that he was positive.

'We were pretty scrupulously safe in the two and a half years we were together...Once, late in the relationship, he penetrated, maybe one thrust and then we both...'we shouldn't do this' and stopped, and I had my wisdom teeth out and perhaps gave him a blow job too early.'

Jon describes Ben as 'the love of my life' but Ben left him for someone else after just over 2 years. One of the reasons Ben gave was that he wanted to be in a relationship with another positive person but also Jon had been acting, working very long hours and Ben had built up a different social circle.

'I was completely devastated and I think I went a bit mad...a complete lack of care about whether I lived or died. I was passively suicidal'.

Jon describes an experience during this time when he went home with a man who had had quite violent sex with him, and Jon deliberately put himself in a situation with this man who he thought might be dangerous. He also didn't practice safer sex.

'I probably wasn't that bad all the time...I was just exhausted by life and I didn't know if I could bear the rest of it...and perhaps also I really wanted Ben back and perhaps it occurred to me that if I was HIV+ it might make a difference.'

At this point Jon became quite involved in spiritual activities. He started sending negative energy to Ben's new partner and then was very shocked when several bad things happened to this person in a short space of time. He was very depressed and began to believe that he was probably HIV+. It was not until he felt stronger that he decided to get tested as he believed that if it was positive he would have killed himself; 'Time, therapy and the gym turned the depression around'. He was very anxious about going mad; he has an uncle who suffers from mental health difficulties, his mother has had a breakdown and Jon believes he is susceptible.

### *Diagnosis*

After another two years, when triple combination therapy had been introduced to treat people with HIV and after Jon was that much further away from Ben, he decided to get tested.

After getting his result, he went home, 'phoned an ex-partner who is now a good friend who was on holiday at the time, rolled a joint and watched 'Alien 3' 'an HIV parable' on video.

For the first couple of weeks all Jon could hear was the doctor giving him the result. 'I wasn't upset, I wasn't surprised, I was very calm...but it was just whizzing...I had to remind myself that it was real, that I wasn't just hypothesising'.

Jon's job at the time involved some contact with children so he decided it was easier not to tell anyone at work. In hindsight he told some friends that he later regretted telling: 'It's been a little bit...'how are you?' in that special way...you can do without.'

Jon says that often people assume he's negative because he gives the impression of being innocent, 'because I am innocent and quite prude-y really!'. At work people assume he is negative although he is the only positive person in his section. Jon finds this very difficult in terms of disclosing. Since his diagnosis he has disclosed three times within sexual relationships. 'The first one...ran off...The second one said 'Thank Heaven for that, I thought you were going to dump me!' and the third one said 'Well I may still dump you, but it won't be because of that!'.

Jon thinks that people who work in the field make all sorts of assumptions about people's status. On the other hand he does perceive himself as different from other people at the clinic:

I don't have as much sex as they do! [also there is] a statistical correlation between academic attainment and negative status...I've got a degree...It's a kind of pissy superficial thing, but it's true...I don't dress in a sexually provocative way and I don't conform to the gay stereotype.'

#### *Work*

Jon didn't really make a conscious choice to work in the HIV industry, his current job was one of three he applied for and he wasn't sure that working in the field would be a good career move but in fact he describes his current job as fantastic. The working environment is assertive, honest, committed, passionate; he loves his job, he's good at it and he is appreciated for what he does. On the other hand, he can be used at work as the token positive person and sometimes it is hard to be immersed in HIV all day:

'You find yourself reading reports that talk about mortality rates and the period between infection and AIDS diagnosis and what CD4 level and viral load mean in terms of your health and these are really large issues for me...I put myself into the chart.'

Eventually Jon says he would like to move on. His work experience to date has been extremely varied and he would like at some point to adopt a career he could pursue for the rest of his working life.

#### *Safer sex*

As part of his job Jon works on prevention campaigns for gay men and looks at issues around disclosure, which of course for him are life issues:

'I spend the day working on it and then go out and try and find myself a boyfriend and those are the very issues I'm dealing with'.

He describes his position now as:

'If they really want me to fuck them without a condom, and they're positive and I'm positive, and that's discussed and that's what they want, I'll do that, but I don't want to be fucked without a condom because it's not safe enough for me, and I would happily tell them that before I had sex so they didn't think it was a reciprocal arrangement. I think you've got to choose your own level of safety and if you talk about it, then that's fine, it's an adult decision.'

Jon's Viral Load is generally about 20,000 and his CD4 count is usually around 600s 'so if I was working somewhere else, I probably wouldn't think about HIV or AIDS all that much...I have a theoretical and a research-based and a professional interest in it as well as a personal interest...I'm constantly thinking of the dynamics of it and what's happening and what's expected and what's ethical...It doesn't seem to me to be an outrageous thing to say that positive men should try not to infect other men with the virus'. He believes that the vast majority of positive men really don't want to transmit the virus but that the issues are not as simple as a lot of people think. He describes a couple of times when he has fucked without a condom with someone who didn't know his status:

'Fairly shortly after I was diagnosed...I was on holiday which probably contributed to it happening, I probably wasn't sorted, and I'm listening to myself now and know I'm making excuses because I think it was stupid of me...I think the modality of sex makes a difference. If I feel I'm being penetrated, then I feel I have less control about whether it's safe or not...I think the active partner has more responsibility. I don't think that's a public health message...it should be both partners, clearly, but it's the person who's doing the fucking who's going to have to wear the condom...and also, as the active partner, you're less likely to become infected...but as a positive man, someone who knows their status, I have not fucked anyone without a condom...Since the viagra [see below], condoms aren't a problem for me any more, so that's OK! I have quite good times being Mr THT. But twice I have been fucked without a condom, and I think part of my self justification process is that they are very unlikely to have become infected. And all the other justification processes you use; why aren't they using a condom, maybe they're positive too; they should be taking responsibility...bad, bad, bad, bad reasonings, not morally bad, just faulty logic.'

Jon feels that the important thing in Health Promotion is not to be judgmental, to enable people to make their own decisions and to respect people's choices, even when you don't agree with them.

### *Good AIDS/Bad AIDS*

Jon feels that these distinctions have changed somewhat in recent years:

'Good AIDS is traditionally children and haemophiliacs and Bad AIDS is gay men who brought it on themselves, and then there is the later Good AIDS Bad AIDS which...so many positive gay men buy into which is Bad AIDS, they went to PSEs or used Backrooms...if it was a loving relationship and 'he lied to me', or oral sex, that's Good AIDS...It's so irrelevant and cheesy...I can't say for certain how I got it but I'd be really surprised if it wasn't unprotected anal intercourse with someone I'd met that evening...quite likely an American tourist...and I don't know who it was because there are a few people it could have been...I'm Bad AIDS'

### *Health*

For the first six months after he was diagnosed Jon got very tired, but he thinks that was because he was processing his diagnosis and that was another thing he had to do on top of his normal life. He now takes care of himself; he still drinks and smokes but 'if I feel tired I'll go to bed, if I feel hungry, I'll eat, if I don't, I won't...I listen to my body a bit more. My body knows what's right, so if it's sending me a signal, I'll obey it.'

Jon actually feels that he needs a certain amount of stress in his life, that he is able to thrive on it and enjoy the challenge, otherwise he would be bored.

### *Mental Health*

Jon describes himself as still up and down in terms of his mental health but he is now much more aware of his state of mind. He has had hypnotherapy which he has found extremely beneficial:

'I thought it was a very passive therapy; you conk out, you wake up an hour later and the next day you find yourself tidying the kitchen or something like that. Instead...there was homework...and I was completely conscious throughout...a bit dreamy maybe but I could hear what she was saying...sometimes when I feel the black dog coming on I think, OK, what did the hypnotherapist say, and do that bit of homework.'

Jon found one period since his diagnosis when slipping back into depression seemed almost attractive. His first relationship since Ben wasn't really working and he was finding his HIV status difficult at that time. This, compounded by being overworked and tired made him 'want to get depressed again...eat cake...slob...just let go...I didn't want the hard work it involves to stay mentally happy and well...I thought I'll just let it happen, and I did let it happen to some extent, I kind of dipped in...and it passed in a month or so'. Jon says there are times when he feels very insecure and needy: 'When I'm in a relationship...I just want them to say 'I love you, I love you', pour affirmations into me and actually it's a bottomless pit, there's nothing I can say, I just go 'Need! Need!'

Jon is currently having psycho-sexual counselling because he has been experiencing erectile dysfunction which he thinks is attributable a number of factors: work, the past instances of sexual abuse, the split with Ben, insecurity about his own body and a declining attraction to his most recent partner. He describes counselling as 'Just me rabbiting on - life's so hard and I feel sorry for myself kind of thing, which I quite enjoy to be honest, but I don't know how much affect it's having'. On the other hand, he has been prescribed Viagra, which has made a considerable difference!

### *The gay community*

Jon describes the London HIV+ gay community as tribal - 'tattoos, piercings, they adopt a look'. Jon hates piercings and says if he gets a tattoo it will be a middle class one!

'I think there is a gay community. I think it's a very diverse community...I think there's enough commonality to describe it as a community...but maybe when I'm saying that I'm referring to the scene...I've no idea what proportion of lesbians and gays in London regularly use the scene...And it would be unwise to posit how many people who don't use the scene were out of the closet or in the closet. There are people in London who are open about their sexuality but just don't think that the scene is for them...'

'...I've lived through really exciting times in terms of gay rights, identity and liberation. [Section 28] ...was when we became a community, more so than we had been before, because we had something to fight against, and it wasn't fighting against

the status quo, it was fighting against something new, a new attack on us and if you look at the figures for Pride marches before then, and then you look at what happened in 1987...and the following Prides...the figures double practically every time. I was really lucky; I lived through it, I saw it happen...hundreds of thousands of people with that increased visibility...

...Now at Pride 'you have the main stage where you have a load of acts I wouldn't cross the street to watch, and you have your dance tent where people take drugs and dance to music which I don't understand because I'm too old, then you have your Indie tent where I like the music but all the boys are spotty and young and have greasy hair...

...I don't really enjoy Pride anymore. And I know I'm kind of old but I'm also kind of young. I'm 32 - it's neither one thing nor the other...I don't feel hugely catered for by the scene or by Pride...

...and with AIDS...they had to put out a booklet to every household in Britain about AIDS which did mention the fact that homosexuals existed and it's completely snowballed...

...And I'm so happy for the generations following me because I think it's going to be so much easier...They can choose which of the gay role models they most like instead of Jon Inman!...'

### *Homophobia*

'...homophobia...is like old toryism...it's really becoming a non issue. The only sad thing is that...in a way it does break down the community...now at Pride there are hundreds of thousands of people and you are not going to get that sense of single purpose.....It's great that now when the police go into a gay bar, people say they're here to help us. When I was young...if the police came into a gay bar, people would stop what they were doing, they would wonder how old the person next to them was, they would be thinking are they going to search everyone for drugs...[and] there was a lot more police entrapment going on...

...When we were a bit more oppressed, when there was a bit more bigotry and prejudice around us, we all pulled together, and as we became more accepted, there's less need for that and so we do become a community based more on commercial tastes and sex, not necessarily a bad thing but it's a bit sad...It's very hard to convince people that we're hated when I think it's very clear that in fact the majority of people don't mind us...'

Jon describes an experience in the park which epitomises these changing attitudes. He was sitting smoking a joint with Ben when some very tough lads, about age 12, came up and offered them drugs. Although they refused they sat down and started rolling joints from their own stash. One of the lads then asked Jon and Ben if they were gay. Jon was really very anxious but when Ben replied that they were, the lads' response was 'Ah, that's really cool, gay's good, yeah'. Their next question was did Ben and Jon like Black people. When they said, yes they did like Black people, the lad's response was 'Oh, I hate them Black people, they're all bastards.'

### *Living in London*

Jon has spent most of his life in south and west London, although he did spend some time living in North London which he hated; he was in a strong Irish community and he says he felt, not so much unsafe as hassled all the time. He then decided to buy a flat in south London because he had friends there and it was an area he could afford. He wanted to live in a community which was diverse and he also wanted to be able to feel safe when he was coming home at night. It was also important to choose somewhere close to places where he could go out:

'Here it feels as if you're in the centre of an axis, because there's Vauxhall, and there's The Fridge in Brixton which I don't go to anymore, and Substation South which I do go to, and then there's Clapham with The Two Brewers and The Kazbar, so it feels like I can walk to one of three little gay enclaves...

...I will stay in London...I enjoy having access to gay people, there's the culture, there's the jobs, there's the transport, theatre, cinema - all those things, but actually it's the gay people more than anything that make me feel I couldn't move outside of London...I would say that my sexuality was certainly a factor in choosing where to live.'

Jon currently has a flatmate in his spare room which works out well but eventually he would like to have the place to himself and get a cat 'But I would have the option that if I meet somebody lovely and they want to move in with me, then that would be fine.'

### *The future*

'...I do want to be in love again. I see no reason why I shouldn't fall in love again and have someone love me. And be in that relationship as long as it worked for both of us. And that relationship will come to an end and doubtless I will rain curses on their next boyfriend and then 5 years later perhaps I'll meet somebody else'.



## **Participant 11 - 'Joe'**

Joe is a 30 year old man who was born in Lincolnshire but came to London to University and has stayed in London ever since. He was diagnosed positive in 1994 and in recent years has had far more difficulties with the side effects of anti-retroviral medication, which has affected his health much more than the virus itself. Joe works in the pharmaceutical industry and lives in West London with his partner James.

### *Growing up*

Joe says he always felt more of an attraction to men than to women, and at about the age of 18 he thought it was time he chose. He did consider a heterosexual lifestyle but felt he probably wouldn't enjoy it as much and that it would be harder to stay faithful; 'On a scale of sexuality I would say homosexual, maybe three quarters'.

Although he experienced some insults at school, it was relatively infrequent and he didn't find it too distressing; 'I've always been fairly happy with who I am'. He's not sure why it's been so much easier for him than for other people, but he thinks it helped that he had very supportive parents and older siblings who were only concerned that he was happy; however he achieved that was up to him.

Joe made a conscious decision to go to University in London as he was 'particularly interested in ending up as an urbanite'. He had found other gay friends and a social group at home but he wanted to be experiencing other things.

Joe's degree was a four year course with integrated work placements so he could afford a 'pretty wild' lifestyle of partying and drinking. He now works for one of the companies where he was placed whilst at university and is very happy there. He feels that the culture is friendly and forward thinking, the work is interesting and the pay is good.

### *Diagnosis*

When Joe moved to London, the people he socialised with were sexually active and weren't too interested in having safer sex, 'unfortunately, I became a bit sort of drawn in to all that which is how it happened I suppose. It was only in 1993-4 that Joe started noticing that the people he socialised with had begun to practise safer sex and he started thinking about his own behaviour. In 1994, Joe began to suffer from ulcers and dry skin. Although he was otherwise healthy 'in my head I added all of it up and thought 'well, it could be' and he did receive a positive result when he was tested:

'It was a process of hooking the pieces up...well there is a chance...it wasn't something I particularly freaked out about or got anxious or hysterical about. I went in there with a fairly clear head, half expecting that I would be alright and half expecting that I would hear dreadful things...but I actually handled it reasonably alright because I think I half expected it.'

At the time Joe was living in a shared house which was 'quite crazy' with lots of coming and going, parties and alcohol, and Joe reacted by becoming quite introverted, 'I wanted to have some space and quiet to think things through and to work out a strategy'. He decided not to tell people until he had things worked out in his own

head, and even then he decided he would only tell the people with whom he felt he could be totally honest:

'At the time I was still very unsure about umpteen things and wanted to be sure that everyone I told would hang on to the information'

Joe didn't tell his family for nearly two years. At the time he didn't want to upset them and while his health was OK he didn't see the need to alarm them; his own approach was that, although HIV was a problem, it didn't need to be seen as a threat.

In the end he was placed in a position where he had to tell his family. Just after he and James met, James told an old friend on the 'phone about his new relationship with a man who was positive. This friend who lives very near Joe's family worked out that it was Joe and, as he is 'a huge blabber', Joe felt the need to tell his family before they found out third hand. They were shocked but supportive, and Joe felt that it helped that by this time he had plans and a strategy of coping which he could present to his family.

It is important to Joe to feel in control of information about his status, he thinks that the sense that you have less of a grasp on your future and on your health, makes it even more important to feel that you have an influence on other things that happen to you.

#### *Anti-retrovirals*

At his diagnosis his blood counts were 'not brilliant' and, although he wasn't ill, he experienced some skin and mouth problems, 'a whole host of small things...which all in all were having an effect on my self image as well...I saw my health as headed on a slope'. He started on a clinical trial, which he found attractive because whilst he was on the trial he was very closely monitored:

It also helps to answer questions in a structured form which can be used to help others in the future. I suppose it's quite altruistic.

At this time there were a few drugs out but the doctors weren't really sure how to use them. As part of the two year trial, Joe had his blood levels checked regularly but he was not given his blood results until the end of the trial 'So I hadn't a clue how my health was in terms of clinical end points, I just had a hunch from my overall health and how I felt.' In hindsight he wouldn't again agree to go on a trial where he wasn't informed of his blood results. He was on an arm of the trial which involved AZT and 3TC which didn't have any side effects at all and at the end of the trial his viral load had gone from 138,000 to 1200. Just before the end of the trial, however, his viral load had begun to creep up again.

#### *'The protease experience'*

At the end of the trial Joe transferred his care to another more local hospital and was put on Indinavir 'which I think out of all the protease inhibitors is the nastiest'. DdI and D4T. He had always had some stomach problems but this combination gave him a most appalling upset stomach:

'So I was feeling really awful all the time, throwing up, on the toilet all the time. becoming slimmer and slimmer, but in terms of my bloods I was excellent because my viral load was down here...but I felt absolutely lousy...there were times I was virtually held in the house because I was in and out of the loo all the time' and it ended up that he was heaving even before he took them, 'with the expectation that if I had them they would have this terrible effect on me'.

He had always been quite a big man but he wasn't eating and was losing weight rapidly. The hospital was very reluctant to change the combination and Joe persevered for 18 months; at the time the only options were to try another protease inhibitor which might well have had the same effect, or to halt treatment 'which I haven't ever really thought of as an option, I think once I had started...I was assuming that I would stay on it'.

Joe describes himself during this time as 'on auto-pilot...I just had to switch off and just try and plough through it'

At the time, he and his partner, James, were living in a very small flat and if Joe was ill, James had to sleep on the floor. They put in for a housing transfer but the Borough's policy for housing HIV+ people was to make a judgement on the basis of the blood results which of course in Joe's case were really good. They appealed to their MP and in fact the Borough's policy got changed 'because we kicked up a hoo-hah, so I was quite proud of that'. They moved into their current house 2 years ago 'which is absolutely heavenly in comparison'.

In the meantime, Joe was feeling worse and worse. They had a holiday in Ibiza which he spent 'just sprawled out' because he had no energy for anything else. On their return Joe was found to be in the early stages of hepatic failure and 'I was finally able to halt the drug there...Virtually instantly I got better and better'.

'That was the protease experience that I never want to repeat again...Hell on earth'

#### *Efavirenz (Sustiva)*

Joe kept the other two drugs and started on efavirenz about the same time as he and James were planning to move house.

'All of a sudden I was aware that I was becoming quite anxious about things ...The thought of having to pack up and move house was a bit distressing' and this was exacerbated by the fact that the Housing Department were being very unco-operative about the move, 'and I was on this drug that was having this really weird effect on my brain, I was just becoming really really anxious and stressed out and freaked out by the whole thing.'

He started the drug in August and by April 'I was virtually sectioned. I was virtually suicidal, crying all the time; I'd become virtually a hermit again'.

From childhood Joe had experienced a slight speech impediment but by his late 20s he had it very much under control, but 'all the anxiety and the strange effect of this drug were effecting my speech as well and I was actually finding it really hard to

speaking at all. This started in the August...By Christmas I was really quite cranky and by April...I was virtually crazy.'

Even though taking the drugs was appalling, Joe felt his options were very limited: 'either this or halt the drugs and all the horrible things which could happen if I stopped them. I pressed on until I felt I was absolutely crazy.'

Joe describes himself as undergoing a total personality change during this time: 'I was aware that I was extremely grumpy, with the smallest thing I would fly into small angers, bang things and slam doors, and I've always been a really quiet person, peaceable'.

Finally, Joe went to the doctor in tears: 'If I can't stop these drugs I'm going to chuck myself out the window'. In the end it so happened that his blood results weren't that good anyway so the doctor was happy to call a halt.

He stopped the drugs in April and for the next 4 months he had a drug holiday. Joe has now been off the efavirenz for a year and a half but he still experiences heightened anxiety whereas he wasn't an anxious person at all before.

#### *The drugs now*

Eventually Joe started a combination of 3 NRTIs plus an NNRTI, two he was already taking plus two new drugs, plus hydroxurea which boosts their effectiveness. He has been on this combination for over a year with no difficult side effects:

'I'm actually feeling brilliant, really healthy. I'm able to get out and exercise...swim and things like that...Whereas when I was having problems with the drugs I would head home and sprawl on the settee and that was all I could do' The doctors have included one extra drug to try to hold on to this combination but they are hinting that he might have to change again the next few months 'which I am dreading' although the doctors are reasonably hopeful that there are new drugs coming through which won't cause such disabling side effects.

#### *Joe's feelings about the drugs*

The drugs have played the most enormous part in Joe's life since his diagnosis, far more than HIV itself which really hasn't directly caused him any health problems at all:

'I saw HIV as a problem which was actually being held in an OK state because of the drugs, so even though I was having dreadful problems on the drugs, I was feeling, at least I'm not having horrible infections and hospitalisations and things like that all the time, which, when I first found out that my CD4 count was in the hundreds, I was expecting that all these awful things would happen, and so I felt happier on the drugs, even though they had a horrible impact, rather than being off the drugs and perhaps having other things happen...having opportunistic infections has always seemed to be the highest in a hierarchy of horror.'

When he had the 'protease experience', there was a certain amount of continuity because he had for some years been suffering from Chron's disease and was used to intestinal 'flare-ups', so in some ways, although it was a terrible time, it was an

experience which held some familiarity. This was not the case with the Sustiva which represented a complete personality change.

### *Work*

Joe has had times when he has felt constantly exhausted, drained and ill. Eventually he decided, encouraged by some leaflets he saw at work about ways in which the company could assist people who were HIV+ within the company to stay employed, to talk to the Head of his area about the situation. He has also over time informed some people at work, in particular the Human Relations Department and Occupational Health in case he needs time off.

Sometimes Joe feels it's all getting to him:

'There are times when I end up...a bit absorbed by it all...I feel if I have to head in and have to handle stress then either I'll burst out crying or I'll holler at somebody and I think they're supportive of the fact that here and there I'll have to say 'Look, I'm drained, I'll have to have a day off'.

He said it would be great to be able to ease off the time spent at work and the stress and anxiety he experiences at work and he has recently applied to work part-time. They have accepted that because they would rather he works part-time than give up work altogether. His struggle with drugs would have been easier if he hadn't had to head into work each day. He will work 3 days which will give him time for resting and he will be on the same salary as he was when he first started working for the company. He will be happier on the smaller income because overall he will have a better quality of life. He loves his job which is great but the downside is that he ends up getting drawn into it which isn't healthy and isn't fair on James, so the aims of going part-time are health preservation and extra time with James. He thinks he will find it quite strange and even hard at first but he is sure that he will enjoy and benefit from the extra time.

### *Relationship with James*

James and Joe have been together for 5 years, since soon after Joe was diagnosed, 'the pair of us intertwined with each other virtually instantly and it hasn't altered.' James has worked in health care and has done voluntary work which has put him into contact with people bereaved through HIV. James says that he feels it was significant that they met when Joe had only been diagnosed 16 weeks, 'so it was a partnership thing right from the start'. It was hard when he was taking the Sustiva because he couldn't really explain what was going on, Joe became withdrawn and James felt excluded and shut out which he found difficult.

### *Gay community*

Joe doesn't see himself as part of an exclusive community. If he is part of any group, he is part of a group of people who have alternative approaches and experiences, but not necessarily about sexuality. When he first moved to London 'I had all these hopes of being part of a huge group of friends who would be in and out of each other's homes all the time and partying...if I think about it now I'm older the whole thought of it is actually quite horrifying!'

Joe says that his interactions at the HIV organisation he goes to aren't necessarily or exclusively with gay men; 'everyone integrates easily because they have an empathy.

having all been through anxious and horrible experiences'. Joe finds that people who have been through difficult times often have a different attitude to life and he finds this attractive in people.

### *Social circle*

This is something that Joe has reassessed quite consciously since his diagnosis :

'I suppose I started to think about other people around me and if I enjoyed having them around me or if I found them overall to be a drain or a pain...I was actually quite harsh about it...I only held on to friendships with people where I was quite clear that things were heading both ways between us...I suppose...the hunch I had was that I shouldn't be someone who just hands out all the time...I actually dropped, purposely, and quite harshly for 1 or 2 of them, I dropped quite a few friends...In hindsight...I'm quite happy about it...So...HIV certainly had an impact on my social interactions...and it was an aspect that was quite important from a personal point of view...I'm pretty sure that it's helped me avoid feeling stressed'

### *Living in London*

Joe certainly feels that there are disadvantages living in London: lack of space, poor housing, people are less friendly, and the traffic: 'I hate the roads down here, I end up hollering and screaming at people in traffic. We're in a hurry all the time'. On the other hand, he feels it would be hard to integrate into a rural area because people in London are more accepting of alternative lifestyles.

When he first left home, he saw moving to London as an opportunity to 'find out more about who I was, to integrate into a community of people with similar interests, outlooks and intelligence.' When he left school, his social group was split into those who were happy to stay in the area and those who went away; 'I was quite pleased that I was in the half that was heading off and exploring'. He found people at home frustrating in their attitudes; snobby and not particularly understanding or sympathetic.

He and James have contemplated moving to an area where they could live reasonably close to an urban area but be in the country, such as the outskirts of Bristol, but there are issues regarding job opportunities for James who is a complementary therapist.

There are also advantages to living in London in terms of your status. First of all, access to medical treatment. Joe feels it would have been harder to access the drug trial when he was first diagnosed as they usually take place in urban areas, and if he hadn't had access to the trial, he would not have had access to drugs for some time, and may have become unwell during that period. 'So it helped my treatment at the start...although there were people on the trial who travelled into London from further away.' If Joe had lived in a rural area, it would not have been impossible to travel but it would have been expensive and involve time off work etc.

Also Joe feels it would be harder in terms of integrating into a community if he was positive in a rural area; if he lived in a rural area he would be far more cautious about who he told about his status. He feels that urbanites are a bit more informed, accepting of alternatives, people in the city are less likely to be horrified or anxious about their own health if they're in the same area as someone positive, whereas this

would be a problem in the area where he grew up. He feels this may be because HIV is more of an urban issue; there are more positive people so other people are more likely to be interested and better informed because it is something closer to home. Joe feels that people in rural areas may not have had exposure to information about HIV. They've probably all heard of it 'and they probably think 'Oh my God, it's here and I'm scared' which is probably quite understandable for somebody who only has a small proportion of the overall understanding'.

On the other hand, he points out that the computer is an excellent source of information and support; 'Even here I'm part of a few groups and we exchange information about our own experience and our own strategies...It helps us feel there are others out there who have the same issues.' It also has the advantage of the fact you can access information without having to ask for help or ask anybody directly.'

Joe says he would be interested to find out how many positive people access information via computer; he read an article which stated that out of all the hits on all the sites across the world, over half the hits are health queries. This of course has implications for pharmaceutical industry, although they aren't allowed to advertise pharmaceutical products in this country, but people can access advertising from abroad and even order the drugs over the web.

#### *Complementary therapy*

Joe has been having massage virtually every week for four years and really enjoys it, 'it helps me to stretch and stay flexible and supple. He has his massage session at an HIV support organisation and has an opportunity to socialise with other positive people before and after his appointment, 'seeing people who have had horrible experiences but who have headed through it and headed out the other side.'

#### *Relationship with doctors*

Joe almost always sees the same doctor and finds him very approachable; he will think about what James says and will take his point of view into account. When Joe was feeling so terrible, he did become a bit frustrated that the doctor wasn't more proactive but in hindsight he was trying as hard as he could; 'there are times when people are in a situation where all the alternatives feel awful and it's hard to choose'. He says that he could have got angry and kept changing hospital, but that wouldn't have achieved anything and, because he has always kept himself informed, he has always been sure that the health care he has received has been of good quality:

'The personal stresses I just accept as being part of the ups and downs which all of us have. There have been some horrible periods, but it's improved. I don't think it's something I particularly dwell on, although I do have anxieties about something similar happening in the future'.

Joe has always tried to keep as informed as possible and refers to some research which implies that somebody has a far higher life expectancy if they are treated by someone who's experienced in the field. He also says that when he was experiencing such debilitating side effects 'I was quite challenging, asking why they were keeping me on the drugs. I was fortunate that they were happy to explain...I helped them to understand that maybe it's important also to look at the quality - if someone's virtually housebound, even if the drugs are having an effect, maybe overall it's not

acceptable...[there was] heated exploration!'. Joe realised that one of the problems was that there were only a limited number of options available and the doctors try to avoid hurrying through options. He also appreciated the doctors' honesty about their relative lack of knowledge and experience. He feels that people affected by HIV are often a group who are able to express how they feel and what they prefer which had played a big part in changing approaches to healthcare, HIV is 'an area which has been driven equally by those who are infected and affected as it has by healthcare.'

#### *Other organisations*

After he was diagnosed, Joe attended a group run for newly diagnosed positive people and found that very useful; 'I was really pleased that I found that information out really quickly [and] it was an opportunity to look at the issues with other people who were equally unsure...It helped ease the anxiety and stress of the experience.'

Joe points out that the travelling time to this group and from his parents' rural home to their local group is exactly the same but the advantage of living in London is that you do have a choice of services. For example, Joe has a friend who found the approach very hurried at his hospital, 'I explained there are other places which offer a better service which try and home in on the person as a whole...he had a hunt around and is far happier now.'

#### *Spiritual beliefs*

Joe says until he was about 26, he was reasonably driven by the idea of a pleasant home, fast car etc. He was aware that there were people in the world with problems, aware that he was fortunate and would try to do a bit to help other people, by donating to charities etc. At the time, however, he socialised 'with people with big egos who weren't particularly thoughtful' and some of that attitude brushed off on him. If he had chosen to be on his own or not to share a house with people who were so hedonistic he might have been more spiritually aware a bit earlier. When he moved out of the shared house and met James, he began to witness and experience 'friendships and people who were close who really tried to improve each other's quality of life and help each other whenever there was an opportunity'. Joe felt far more at ease with these groups of people.

Joe also feels his experiences have given him an insight into other people's distress, they opened his mind up, drawing him away from an emphasis on material things onto being happy and trying to improve people's quality of life; 'so I suppose HIV has had an impact on my spirituality, through all the traumas and dramas of all the side effects...In spite of having all these horrible things happen, I'm happier than I've ever been'.

Joe is unsure about what he believes about life after death, although if there is reincarnation he would like to end up as a dog! 'I have a hunch...that I think it might be our own pride that makes us think it's impossible that we'll ever end...I wonder if that's part of our self importance...I'm unsure, but if there is anything afterwards I hope it's easier than life on earth, because it is a struggle and it isn't always enjoyable and it isn't always pleasure. I think that after having had that experience of struggle and ill health and intense anxiety, I think the thought that in the end there is a place afterwards...where things are easier...I think that would be nice, but I don't have any strong thoughts either way'.



When I asked Joe if there were times when death seemed close he replied 'I don't think there were any times when I felt it was impending, I think there were times when I felt it was possibly closer than I felt totally comfortable with!' When he had hepatic failure he made a will which leaves everything to James.

### *Daily life*

Joe finds the vestiges of anxiety caused by the sustiva quite frustrating. He adopts various strategies to try to avoid anxiety provoking situations and also tries to do things which ease anxiety and stress such as exercise, swimming, shiatsu, easing off at work etc.

On the other hand, one of the joys in his life at the moment is the simple one of 'being able to head out without having a complete plan about how to find a toilet at a second's notice'. He also loves his home and enjoys spending time at home.

### *A typical day*

Joe describes himself as most definitely not a morning person! He tends to get into work by about 10.00 where his job consists of helping people with their projects, providing support and also working out ways in which the work can be done more quickly and efficiently. He may have appointments or may just get on with paperwork.

Twice a week he has an evening class and if it's a day when he has an evening class he heads off reasonably early, otherwise he works until about 7pm. On the days when he's out in the evening James will cook, otherwise he cooks as James also has classes on different days. At the weekend he and James don't go out that often, although they may go over to friends' or have friends over. They might get up late, go shopping, potter in the garden, watch TV.

Joe used to drink heavily but now no longer does. He believes that the body gives you hints, you get a 'hunch' which you should follow, for example since the hepatic failure he has drunk a lot less than he used to, similarly he has recently cut down on smoking cannabis which he feels probably isn't very good for his chest.

### *The future*

Joe says he swings between different extremes when he looks at the future. He is afraid that his current combination will cease to be effective and they will not be able to find another. He is also afraid of any change in the medication because the side effects can, quite literally, be fatal. On the other hand, through his work he is able to keep abreast of all the changes in the field and probably spends more time on the hopeful end of the spectrum.

He and James have got into the habit of avoiding plans, because when Joe was so ill he could only manage day to day. Now they are gradually making more plans for the future and giving more thought to how they can improve their existence and have an easier and happier life.

### **Participant 13 - James**

James is a 31 year old man who lives in a West Yorkshire town. He was born in Reading and has lived in several areas in the country and in France and Wales during his life. His father died when he was 9 but his mother remarried and his stepfather has been his father for longer than his real father. After many years working for a brewery, James has recently started working in the travel industry.

#### *Growing up*

James describes himself as quite a loner as he was growing up. He had friends but he didn't socialise much. He comes from an upper middle class background - a childhood which involved horse-riding, the hunt ball, young farmers, scouts etc 'the norm for my...peer group'. He did those things because it was expected of him and didn't really question it at the time. He grew up in a village community where everybody knew your business. He has been quite selective in choosing to whom he tells his status out of his mother's friends and family.

In some ways James was more aware at the time of class differences between him and the other children at school, and differences in lifestyle. For example, he can remember a child in his tutor group who used to get £5 a week pocket money whereas he got in pence however old he was plus a zero. He also talks about how he was taught strict table manners, he was forbidden to eat in the street etc. He feels that these lessons have helped him in life to be seen as someone who comes across well and presents himself well 'it's a social etiquette that people do notice and most people will respect you for it'. Another aspect of his upbringing which has endured is not wasting things, boiling up the end of a joint, using scrap paper etc. and also not wasting your talents. James feels he has been very strongly influenced by his mother and his grandmother.

'If you don't have some sort of discipline in your life you just bounce around from pillar to post...if you don't learn something everyday it's a day wasted...that's the philosophy I've been brought up with.'

James describes Christmas as very much a family time from when he was very young. On New Year's Day his mother for years has had an open house party and James and his brother were expected to be there and to assist. He says that the sight of all his family gathered together gives him the feeling of going back in time.

His mother has had a difficult life. Her brother was killed when she was 14 and her father died in the same year. Her stepfather died in 1964, her father-in-law in 1976, her husband in 1977, her mother and mother-in-law in 1992, her older brother in 1998 and James said that when he was diagnosed 'all that went through my mind was that she was going to have to bury me'.

James was called names at school, but he never really took much notice. It got him down sometimes. 'kids...can be more cruel than adults can be.' He had an idea at quite an early age that he was gay, but he suppressed it and had girlfriends at school and college. 'but I always knew that it wasn't totally right.' He had a friend with whom he went skinny dipping. 'just boy things' but for James it always had a different slant. At

that time there weren't programmes like 'Queer as Folk' and when Eastenders had a gay plot-line 'I couldn't wait to watch it'. James points out that you can buy Gay Times and Attitude in any standard newsagent and they're no longer on the top shelf. Attitude is the equivalent of a gay man's GQ - it's been made more mainstream and lads in their teens can buy these magazines more easily.

James says he can see the issue underpinning Clause 28 about protecting young people, particularly in a rural community where a young person could be very isolated; you might come from a village where there are only 2 or 3 other people your age, and you go to a small school where everybody comes from the same sort of background and so has the same sort of outlook. At James' school there was only one black lad in the whole of the year:

'Minority groups which were visual minority groups weren't there, so a minority group which wasn't necessarily visual, was even harder'.

He feels that educating young people about gay issues might encourage people in the class to pick on somebody who is perceived as different. He feels nowadays that young people grow up a lot quicker.

James said he was late in Coming Out, not until he was in his 20s. Until he learnt to drive he wasn't really able to get around. 'I knew it was all out there but I couldn't get to it' The nearest gay scene at all was over 20 miles away, 'and I didn't know anybody else...if you live in a village and it's got one bus a day or something ridiculous and you know on a Monday you can go to Darlington and back...and if you want to go anywhere...from the upper middle class family I'm from, parents took a lot more interest'. At college there was a café nearby which was gay run, and then later James moved to Newcastle which was 'vast' in comparison.

'I remember driving from the house and...parking outside one of the gay pubs in Newcastle, and watching people go in, and plucking up the courage to go in, and eventually I went in and it was...awful, horrible, but I persevered and went back and went back and I eventually got to know people'.

While James was growing up, he didn't talk much to his parents. When James told his mum that he was gay, she didn't have anything against it but it wasn't seen as socially correct, now he says his parents are more comfortable with it. His mum asks him how he is, 'but she does it in her way of doing things, which is the way I've always known so it's not strange to me anyway'. She 'hasn't got anything against it' but has made it clear that she wouldn't be able to accept anyone sleeping with James in her house, 'but then again she's changed and she did'. James is quite careful not to tell his mother certain things because she will worry, 'it's easier just not to say anything'.

When I interviewed him the first time he had just dyed his hair blond and he was dreading his mother's reaction. Sure enough when we met for the second time he said that she had strongly disapproved! He went to have his ear pierced, which of course is totally acceptable amongst gay men, 'but in home society it was frowned upon...she would have a fit if she knew I'd had my nipple pierced!...but it's me being gay, me being a gay person, it's one of my three lives and sometimes they have to overlap in that respect'.

James' mother remarried when he was 14. At first he resented his stepfather because he was not his father, but in fact he has been very supportive about his sexuality and about his HIV diagnosis, 'I can't fault him on it'. When he was growing up, however, his stepfather was quite strict - James and his brother would have jobs to do and if they weren't done their pocket money would be reduced. There were locks on the TVs so that they couldn't watch them until the jobs were done. His brother used to end up owing his stepfather! And his stepfather would never forget how many penalties they had incurred during the week... 'I don't think it's made me a bad person'.

He compares his attitude to someone he has just started seeing who is younger than him. James feels he has responsibilities, things he needs to do, whereas his partner doesn't have any responsibilities and can go and get pissed any night of the week. He doesn't think this relationship will last because he has a more responsible attitude to life, and this is partly because of the age difference and partly because of his upbringing. 'You know you've got responsibilities and you can't shirk your responsibilities because if you do, something's going to go wrong'. James says he is quite happy not to go out during the week; he has other commitments and anyway he doesn't actually want to be in the pub every single night. He would rather go out occasionally and then it feels special.

#### *Living in Yorkshire*

James finds living where he does has both positive and negative aspects. When he originally moved to the area, posted by the brewery, a very close friend lived in the next street. She has subsequently moved away but he says that he does not want to move back to the south east, because although people are more accepting of difference in the south, they are less friendly on a day to day basis; in the north 'you build up a rapport with people, even though you don't know them'.

James says that people keep an eye out for each other, like when he goes away people keep an eye on his house. The next door neighbours he suspects are drug dealers and he uses this as an example to show that people do start to talk if you're not careful. He is actually quite anxious about the next door neighbours as there is a lot of coming and going and 'life's hard work as it is'; he worries about his car and also if people got talking about his sexuality, 'it would only take one person who had a thing against it...you never know what the reaction's going to be so you end up always having to live this sort of second life'.

'I have three sides to me'; he is the dutiful son at home and responsible at work; 'then there's me as a gay man; and then there's another side to me, I'm a gay man with HIV'.

#### *Diagnosis*

James was diagnosed in Newcastle in January 1998. The positive result came as a complete shock. He had just started working as assistant manager for the brewery and he started having night sweats and difficulty swallowing. He was also rapidly losing weight. His GP referred him to a consultant and James was immediately admitted. He was then referred to an HIV ward in a nearby city. This ward was known as the HIV ward and when the manager at James' work found out what ward he was on, he asked James directly if he was positive. James had only been diagnosed a matter of a couple

of days and couldn't think what else to say so told him the truth. 'He was a busy body arse-hole'.

James was at that time due to move to another pub as a full assistant manager. As he and a friend were clearing his stuff out of his flat, the manager discussed his status in front of his friend; it was clear that the information had not been kept confidential 'And by this time the whole company knew', so from that point on, even when he was transferred to different areas, James 'had to work knowing...that 9 times out of 10 they would know my status'. James had to work very long hours and felt he had to do this unquestioningly because any perceived failure to measure up could be blamed on his HIV. At one point he had one month off with appendicitis but went back to work too early. So when he later got shingles he felt he didn't dare take any time off so he continued to work a 7 day stretch, 16 hours each day and the Clinical Nurse Specialist came to see him at work.

James was then transferred to another pub whose manager was extremely homophobic. It was at this point that the European Directive for a maximum 40 hour working week came out, but James 'didn't dare not sign against it' because they would never have given him a pub of his own if he didn't work the hours. A few weeks later he got kidney stones as a result of indinavir and this was when he received a letter from Occupational Health. 'I got myself obsessed with work'.

'They never had a chance to criticise my work because I was good at my job, I don't care what anybody says'. However, after working a particularly hard and long stretch, James suffered an anxiety attack and was admitted to hospital. He was signed off sick and in fact at this point the Area Manager was 'totally amazing'. She found him an administrative job which was a flexible 30-39 hour week and 'from there it was OK'.

James' new job involved checking the accounts of a pub where the managers were fiddling the books and they reacted by implying that he shouldn't be doing his job because of his health. James got very upset by their allegations and in the end decided to leave. He now works for a travel company which involves regular hours and is a good working environment. He hasn't told the owners of the company his status but he has told colleagues who have been fine; they have all got degrees and although he is anxious not to sound snobbish, James feels that a university education tends to make you more broad minded. One of the reasons he hasn't told the owners of the company his status is not because he thinks there would be prejudice but rather he fears they might be stifling in their concern.

### *Relationships*

James thinks he probably infected his ex-partner, as he thinks he probably was infected a few years before: 'I know everything should have been used and protected but...just one of those things'.

A few months after his diagnosis James started a relationship with a man who was negative. After a while, however, there were strains in the relationship and HIV became more of an issue between them. They talked about the risk variables and James wasn't happy having unprotected sex, but then his partner started to say that he didn't like using condoms and that he was making the choice and taking responsibility when they had unprotected sex. James wasn't comfortable with this and after four

months of unprotected sex insisted that he have an HIV test, 'I was on tenterhooks for weeks'. It ended up that James was avoiding any conversation or any situation which might lead to sex. He says that when he feels well he feels more in control, but when he doesn't feel so well he worries if his blood counts are up and in terms of being infectious, he doesn't know if he's 'above the line or below the line'.

His partner then 'did something really stupid'; he put himself on the web as a male escort. Meanwhile James was feeling that it was his fault that the relationship was falling apart and then suddenly found out that his partner was advertising on the web. There were problems in the relationship already; his partner had persuaded James into a marriage ceremony and had taken his surname and James was feeling that things had got too heavy too quickly. He also refused to contribute financially or to the housework.

James says that one of his difficulties in relationships is 'I seem to attract people who want to be all on and sometimes I just want it... to be light and frothy rather than the world at war'. He says that 'all I want to be is gay guy with a dick'; he wants to be accepted as being normal, 'you do become very protective towards yourself...it's wrong that you do it, you should be allowed to be who you are'.

James would like to be in a relationship again but with a person who would respect his space and also who wasn't depending on him in terms of housing, finances etc. It is hard for him to find the right person and the HIV 'brings another complication into the scenario...I'm 32, I shouldn't have to start scratting around, tiptoeing around, nobody else does'

'I don't want looking after...I just want to be...a gay guy with a dick, I want someone to love me, or like me...for who I am, not what I've got'.

In the end he is happy with friendships rather than putting up with a relationship which isn't working. At the moment [at the second interview] he's seeing someone but he's made it clear that he's not going to commit to anything. He's said, 'Don't pressurise me because as soon as you try to pressurise me into anything I will back off so fast'. He's explained to his partner that he needs to have time to himself and he needs to do his own things. He does, however, find him frustrating and compares him to a 'little yappy dog who's in your face all the time'. He found it very annoying the night before when his partner was drunk in a straight pub and putting his arm around James. 'That is asking for trouble...there's a time and a place...I can do camp but last night when we were in this pub, he was as camp as Christmas and I was cringeing. I just can't hack it, I can't do camp in a straight environment. Not in a straight pub on a Friday night at 10.00...be loud but not with a Mary voice to go with it...again it comes to the way I've been brought up, at the end of the day you keep your own counsel...you don't know who's going to be about...I've always been taught that a good name is worth keeping, but if you've got a bad name, it takes a hell of a lot to get your good name back again'.

James says that he doesn't want to hurt his new partner but he would like to let him down gently.

### *Clinic visits and medication*

James still travels to his original clinic for treatment which involves leaving home at 7.15 for an 11.00 appointment. Because he gets his drugs through an infectious diseases ward rather than a GUM or HIV Clinic he has to pay for his prescriptions - £80 per year. He has been on the same combination for two and a half years; AZT, 3TC and indinavir, which was replaced by nevirapine after the kidney stones. Now he takes combivir so it is only a twice daily regime. James takes the medication most days but when it suits him rather than sticking to a rigid regime because he doesn't want to let the tablets rule his life. For example, the previous weekend James had gone to Manchester. He didn't plan to stay the night but he ended up staying over and missing his medication so he took one dose 6.00 on Sunday night and again when he went to bed,

'It's the only thing in an average day which makes you think about your HIV status'

James decided to stay with his original clinic 'because they know me and I can call on them at any time'. He also had a bad experience in a local hospital when he was admitted with kidney stones; he felt that he was at risk of infection, he was put on a noisy, busy ward and he didn't feel the staff were sympathetic. It is, however, inconvenient for him to travel so far to the clinic as he has to take day's holiday from work.

### *Other services*

James used to go to Body Positive in Manchester but now this is difficult to access because of work. There is a local HIV support organisation but again they don't run drop-ins in the evening so it is difficult for him to access. James said it is very difficult for him to make any contact with other HIV+ people locally because the community is so close knit and people are anxious about confidentiality so many of them travel out of their area to access support services, 'here people want to be so damn private'. He says that he can understand why and he doesn't want everyone to know himself, but he still finds it immensely frustrating that he cannot make contact with other HIV+ people.

'Some people make a career out of HIV...if you go to some of the centres...those people who do make a career out of it tend to be the ones who are all doom and gloom all the time...you know there's the possibility that all these things might happen to you, but you'll deal with it when it when it arrives'. James says that it tends to be the people who don't work who have the 'doom and gloom attitude', and he doesn't really want to be pally with them, 'sitting round their house drinking cups of coffee and doing the 'Oh woe is me'...it's not mentally healthy...I'm not wanting it to be a career, my life is my career'.

### *Spiritual beliefs*

James was brought up in the Church of England and both his mother and step-father are active in the parish. Again he says that Church, Sunday School etc. plays an active part in the social life of the village and played an active part in his growing up. He doesn't disbelieve it 'but I wouldn't say I'm fanatical about it. I just plod along'. He talks to his (dead) father and he isn't scared of dying, although he doesn't have any clear belief about what will happen to him after he dies.

### *Importance of work*

James is reasonably well paid although his parents have also helped him out financially; they bought his house and his new car, but more importantly work provides James with a purpose in life:

'I count myself lucky, the fact that I am working and will carry on working as long as I can. I know exactly what will happen; I will become ill before I'll give up work and I'll try and plod on because that's the sort of person I am'.

James realises that he throws himself into his work, partly because he wants so passionately to be able to continue working.

### *Attitude to life*

James says he tries to sort out problems by himself, but sometimes he does what he calls 'building a tree'; he looks at one problem which is the trunk but then there are problems attached to that main problem and other problems attached to those and James says he can get into a 'what if, what if' frame of mind.

James went to a weekend 'AIDS Mastery' course which he feels fundamentally changed his attitude to how he approaches life as a positive man. He wasn't very sure what it was going to involve so he went with a very open mind. 'You've got to go with a view that you'll get out of it what you want to get out of it'. The idea of the Mastery course is that you break your patterns and readjust your attitude. James felt his attitude was his 'problem tree' and this was what he was trying to change.

'It was nice just to know that you could be yourself, nobody was going to judge you...it was nonpolitical...It gives you time in an environment...your own daily life doesn't give you the chance to think about things...you've got no distractions...no hassles...you're cocooned in a bubble for that weekend...it's that release that you don't get in an ordinary environment'.

James has found he hasn't always been able to continue the relaxation exercises etc. he learnt on the course because 'your every day survival is more important than your long-term mental attitude...you cope with things on a day-to-day basis'. And it is tempting to stick with your routines because they're safe. From time to time however it's important to break the patterns and do something a little bit different. James also found it a good opportunity for social interaction and to meet people who may have HIV or been bereaved, it gave him a wider view. He would be very happy to go again because he thinks he would get different things out of it a second time.

His (now ex-) partner was very threatened by the fact that James went on this course on his own and didn't get in touch while he was away. When James returned from the Mastery course he confronted him with the internet issue and his partner took an overdose. Eventually, however, he left and James got the new job.

James says that when he was first diagnosed he gave himself 2 years to live although the doctor said it could be 10. His attitude is that it is a chronic rather than an acute condition, but it is still a terminal one.



'I think I'm fairly cool with it myself. I have my own issues but everybody has their own issues regarding anything. My biggest thing is that I want to meet other people and I just don't know how to go about it'

James went to the National AIDS Conference in the previous year and found it very useful to meet other groups of people affected by the virus, again he felt that it broadened his outlook.

'It's made me a stronger person having HIV...it also makes you a weaker person as well...because you feel more vulnerable.'

James says that he makes plans for the future but he also lives on a day-to-day basis, much like anybody else. He has some regrets; sometimes he wishes he had put his degree to better use and sometimes he feels annoyed with himself because of the virus, 'sometimes it does restrict you' and he certainly feels it has restricted him in terms of career and earning capacity because he couldn't keep the hours up when he worked for the brewery.

'At the end of the day I've got my car, I've got my job, I've got my cat, I've got my things around me...I can't dwell on it because it's past and at the end of the day I'm still alive'. Other beneficial things in his life include family and friends. All of these things 'are all very well' but he still feels that he needs a link with someone with HIV in order to enable him to cope. His health is important to him but he doesn't panic about it particularly.

James says that HIV fits into his life where he wants it to fit in, for example he is pretty relaxed about when he takes his drugs because he doesn't want them to rule his life. He's been advised to stop smoking and drinking, but he wants to have some quality of life and there are only so many sacrifices he is prepared to make. He refuses to be fanatical about the way he lives with HIV, 'obsessions aren't healthy'. He doesn't like other people worrying about his health and he doesn't want people 'pussy footing around me'. 'You can't live on the edge all the time, because there's always the fear that you're going to go over. You have to be able to take a step back and look at the wider view'

James says that he tends to try and avoid confrontation with people he doesn't get on with, he'll try to avoid them rather than confronting them; life's too short and he sees no need to hurt other people unnecessarily.

### *Daily life*

James says he's certainly not a clean freak and he does like clutter but he always tries to make sure his house is clean, and he always tries to make sure he cooks for himself rather than living out of tins. He knows his upbringing was old fashioned and in some ways Victorian but he is happy with that.

James sets store by the idea that, although he might make mistakes, he will learn from them. He feels he has a strong sense of where he draws the line between what is an OK and what isn't an OK way to behave. He feels it's particularly important if you're living with HIV and if you're on medication that you have rules and parameters and that you live within these.

James is a 'car nut' and between the two interviews he got a new car of which he is extremely proud! He spends a lot of time in his car and looking after his car.

### *Gay pubs in the area*

James is finding himself limited in what gay pubs he feels comfortable to access. He had a 'bad experience' in one pub in a neighbouring city so doesn't want to go there again, and he's trying to avoid someone in the gay pub in another nearby city. A while ago he went to one gay pub and had a wonderful night, going 'back to being who I was before I was diagnosed'. He met a nice guy, gave him a lift home and was asked in for a coffee. This man was James' age and James thought he would be OK about telling him his diagnosis, 'I told him and he just went ballistic, hit the roof. I thought I was going to be punched...I quickly made a major exit and got home to find snotty messages on my answer machine...I was quite happy for it to be a friendship and he just went beserk...it's a different sort of rejection when they turn round and make you feel like you're dirty...like saying you've got nits when you're a kid at school'.

James said he had a similar situation very recently; he met a man on Saturday night and spent the night with him. He now is faced with the dilemma of when to tell him his HIV status. He wonders whether it will make a difference that this man is more educated. Although he slept with him they didn't do anything which would have placed him at risk. The problem is that until James decides how he is going to resolve the situation he has to avoid that particular pub as well:

'I've done the initial thing, exactly the same as what he's done, we've both worked out that we're both - we get on with each other...there's a bond already there, but this bond can be so easily and so quickly severed, completely, because of one thing I say to him...I get myself so worked up about it, I'll just not 'phone him and then he wonders what's going on, he's not interested, forget it...and the next time you go out and bump into him you feel a prat'.

### *Gay 'community'*

When James first Came Out he was on the scene constantly and it was the 'be-all and end-all'. Now he says he can dip in and out of it 'and that's the thing most people tend to work towards'. It's only a part of him.

A big difficulty for James is his lack of contact with other positive men. He isn't necessarily only looking for a partner, he is also looking for friendship with someone who 'understands your thought from day to day...I don't want to talk about it every five minutes but I would like to be able to talk about it as and when'. In his previous relationship his partner would be worried if James said he wasn't feeling well but would be angry if he felt he wasn't kept informed - 'it's a vicious circle'. When James first moved to the area he contacted the local HIV support service and said that he wanted to be put in contact with other positive men but the only person he has been put in contact with instantly wanted to start a sexual relationship which James didn't want. James feels that the HIV community is diluted in Manchester but is stronger because people come in from outside and because the gay scene in general is so immense. More locally it is more concentrated - one or two people in a small area. People will acknowledge each other in Manchester but more locally they won't.

'I desperately need to find some other people, for my own comfort and...to make sure my own quality of life is how I'm wanting it to be, because at the moment I don't feel a whole person. There's a little bit missing and it's that main bit of the damn jigsaw that's that crucial bit, that's got the puzzle question on it'

### *The future*

James has been offered a post abroad through his new job and whereas before his diagnosis he would have leapt at the chance, now he is more cautious about starting life again in a totally different environment.

James says his dream for the future is basically to be happy. He would like a relationship, he would like to see his job going a little bit further but at the moment he's quite happy, although he would quite like a bit more disposable income. He is very happy with his house, and it would be big enough if he got a new partner as well. He used to party a lot more and sometimes thinks he's boring. In some ways he misses not partying so much, he feels that maybe he's getting old, but in some ways he feels that the fun you can have in your 30s compared with your 20s is 'more whole, more rounded' whereas people in their 20s are often still bouncing round from pillar to post.

### *Meeting Shaun*

As a result of what James has said during the first interview, I put him in touch with Shaun, participant 1, and they met up in the period between the two times I met up with James. During his second interview he mentions several times how beneficial it was to meet up with Shaun and talk about HIV with someone who understands - 'You have to nurture that side in your life in some ways because otherwise you're not going to achieve anything...we talked about it but we also joked about being HIV'. He felt it was such a relief to talk to Shaun, partly because the interest they have in HIV is a mutual and a vested interest.

## **Participant 14 - Swaile**

Swaile is a thirty five year old man who lives in a town in West Yorkshire. He has been extremely ill and was not expected to live but has recovered some measure of health. He lives in a nursing home in a town in West Yorkshire.

### *Growing up*

Swaile describes himself as quite a rebel at school; for example on one occasion he was going to be caned by the headmaster for smoking 'and I grabbed the cane and whacked him over the head with it'. When he was 11 he was sent away to an approved boarding school. He often used to run away and sleep rough. He went to a park in a nearby city 'and this guy comforted me'. He was in control of what he agreed to do sexually because there were things he didn't like 'but they used to treat me alright, they used to take me on holiday, take me to their house and they'd feed me and look after me all week...I wasn't on the game...if they gave me money I didn't ask for it, they were just giving it to me out the kindness of their heart...more like a sugar daddy...I didn't ask to be looked after, they just did it automatically...they were treating me as if I was a woman'. There were several men who helped Swaile in this way and it was definitely preferable to school.

Swaile also had relationships with women, both older women and women more his age.

His parents didn't find out about Swaile's sexuality until much later and then he blamed it on the school. In reality he doesn't know how much was attributable to his upbringing, 'basically I've enjoyed my life'; he's never been coerced or forced into anything.

'I hated the school' although he got on well with the other children there. He went home at weekends and holidays. They would start off with 10 points every day and you could gain or lose points and this would affect what privileges you could get, although Swaile often would end up with 0. He got on alright with individual teachers 'but I just rebelled against the system'.

When he left school he got a job in a warehouse but he has continued to have relationships with men who have looked after and supported him throughout his life up to the present day. For example one man taught him how to drive and they still see each other today although now just as friends.

### *Geography*

Swaile has lived in West Yorkshire cities or satellite towns outside them all of his life. He spent a year and a half in a bail hostel for a crime he didn't commit and of which he was cleared, but by the time he was released he was homeless because he could only keep his council flat for 12 months. So then he moved to another city in West Yorkshire and this was when he got his diagnosis. He was given temporary accommodation and then moved permanently to a small town in West Yorkshire. Then last year he moved into a Nursing Home.

### *Living in a Nursing Home*

Last year Swaile was very ill and was expected to die. The other residents are largely older than Swaile and he has told them he has cancer, although the staff know his status. He was wary of giving up his flat and he was worried that going into a Nursing Home was going to be like going back to Approved School, but he says it's more like retiring. Also he is able to come and go as he pleases and do his own thing. His room is only small but it's 'alright' and he says he's only in the Home because he can't cook; at home he wasn't eating properly. He needs help getting into the bath but apart from that the only thing he doesn't do is cook for himself. He simply treats the place like a hotel.

### *Relationships*

The disadvantage is that if he met someone he wouldn't really want to tell them where he lives. If he took someone home with him 'I think someone might tell them what I've got, and then they'd run a mile'. A couple of weeks ago he bumped into an old girlfriend 'went back to her place and one thing led to another, it were OK' but when she asked him where he lived 'I just said I lived in a mansion!' He will always use a condom now but his girlfriend was surprised that he wanted to use one. He chose not to tell her his status 'because she wouldn't have gone with me, would she; nobody in their right mind would, would they?' He always has one or two condoms with him just in case he bumps into someone. 'It's not often that I meet anybody new now, it's just old flames tempt me'. If he met someone who was positive he would worry that they might be in a worse state of health than him.

### *Diagnosis*

Unlike all the other participants, Swaile identifies more as bisexual than gay. He feels he was very uninformed about HIV because he regarded it as a gay disease transmitted through anal sex, and as that wasn't a sexual activity he engaged in, he didn't consider himself at risk. He was actually infected by a woman, but he had thought he could only be infected through unprotected anal sex with a man.

Swaile was in a relationship with a woman who he knew was a drug user and was ill but he had no idea it was AIDS. He found out when she was murdered in 1994. He was arrested on suspicion of murder; the police thought he had murdered her because she had infected him and that was the first time he had any idea she had AIDS. 'I was fit as a fiddle, I could run, I could play football for England'. In fact the man who had murdered her had been infected by her and that was his motive.

It wasn't until September 1995 that Swaile actually got tested. He didn't go for a test at first because he was totally healthy. It wasn't until he had a swelling in his neck that he went to the GP 'and he knew straight away it was more serious'. He was referred for an operation and the consultant said he had AIDS and he was tested; 'then everything fitted into place'.

'I'd like to think she didn't know she had it but I'll never know...she's dead and buried'. He thinks she probably didn't know. Whereas he now knows and would be careful in any sexual activity.

He had a very open relationship with this woman. He knew about her alcohol and drug addiction. She'd been married and had four different children to four different

men, she had a criminal history 'and I knew all about this but I still shagged her'. He was able to be equally open with her and it worked out for them both. They were still together at the time she was murdered.

Swaile didn't know anyone who was HIV+ prior to being diagnosed, but since his diagnosis he has met people at two local HIV support organisations.

### *Parents*

Swaile's mother died in 1990 so she never knew his diagnosis and his father thinks he's got cancer; Swaile says he wouldn't understand about AIDS. He and his father are still in touch and get on OK. 'I don't blame them for sending me away, I just rebelled'. He has two sisters who know his diagnosis and his brother 'who was funny about it at first but he's alright about it now'.

### *Telling people*

Swaile is strategic about who he tells his diagnosis and he hasn't come across any prejudice. All his friends know his status and they're alright about it.

### *Health*

Swaile was expected to die quite some time ago. He has experienced numerous health difficulties as a result of HIV, not the least of which was stomach cancer which caused his stomach to bloat out and he needed a drain. It was expected to be terminal and he was admitted to a hospice. He ceased taking any medication because there didn't seem to be any point but he has actually continued to live in the face of all medical prognoses and says he will just carry on for as long as he can.

Swaile paid for his funeral assuming he was dying, but he 'just carried on, each day as it comes, I kept waking up every day and I'm still alive...I always said there's another chapter in my life but I don't know what...there's more living to be done'.

He doesn't feel that his health is too bad, sometimes he feels really fit and as if there's nothing wrong with him. He regards the decline in his health since his diagnosis as going into retirement at an early age. He feels that the only thing that HIV stops him doing is football; he can still walk and still catch a bus.

### *Daily life*

He gets up about 10.00 and goes to watch TV and have a few smokes and then goes back to his room to listen to music. Music is a very important part of his life, he likes Rolling Stones, U2, Simple Minds, David Bowie, Queen, 'stuff like that'. He goes out once or twice a week into the nearby city, meeting friends, window shopping etc. He gets £15 plus the Mobility Component of DLA which is enough to manage.

### *Medical treatment*

When Swaile was diagnosed he got nothing - no counselling, no medical treatment; he was simply told that he had AIDS and that it was terminal. When he moved he was put on dual combination therapy and he did well for 18 months, but then that combination failed and the new combination made him very sick. 'I decided just to give up the medication and now I don't take any...I feel I'm doing better without it'. He has been off medication for about a year and doesn't go to the hospital regularly. He is visited by the nurse at the Home and she administers pentamidine as a pcp

prophylaxis. He also takes TB tablets to prevent his neck from swelling up again. He no longer has his blood levels checked regularly because he's not on any medication so it doesn't feel worth it.

#### *Other services*

He got put in touch with the local HIV service who have paid for him to go to Greece for some respite and he goes to the drop-in once a week. He has had complementary therapies in the past but when his stomach was very bloated it was too uncomfortable so he stopped, but he is considering starting them again.

When Swaile was younger he rebelled against the social workers 'but I don't bother now' and he feels he's been treated OK by social services. They visit him once a year to check that his placement is still working for him.

#### *Gay community*

The men Swaile used to see used to take him into gay pubs, they also used to take him abroad on holiday. He was very good looking when he was younger, and he says he might shave his beard off and get dressed up nicely and then he would look younger. He used to meet men in parks and in bars, but he doesn't go out much on the scene nowadays.

#### *Attitude to life*

Swaile describes himself as a very easygoing person, and he very rarely finds that things get on top of him. 'I enjoy life and enjoy it to the full'. Sex is still important to Swaile. He also likes music, going into town and meeting his friends.

#### *Spiritual beliefs*

Swaile was born a Catholic but doesn't go to church now. He believes that there's another world afterwards 'but I don't want to find out just yet'.

#### *The future*

Swaile is adamant that he won't go back on medication. He believes that there is another chapter of his life left to be lived but he doesn't know what. He will wait for it to unfold.

## Participant 16 - Gareth

Gareth is a 32 year old man who was born and brought up in a small village in Surrey. He was diagnosed in 1997 and now lives in London with his partner, Stefan (participant 8). He is completing his nurse training.

### *Growing up*

Gareth describes his childhood as 'a blur', as if it happened to somebody else and it was only when he left home that his life started. 'It wasn't that great and I think if it was worth remembering it would be more a part of my life now'. He always knew that he was gay but it was something he kept to himself. He didn't have a great Coming Out; he simply moved from being a child to being a gay man; 'I never really rammed it down anybody's throat...I just happened to sleep with men.'

He is in touch with his mum but not his dad. He decided to tell her and there was a big build up, he got drunk and managed to tell her and her response was 'I've known anyway, love; I've known since you were 15'.

### *Gay community*

In the area where Gareth grew up 'I was the gay community'. There was one gay pub in the nearby town and he would go there with his friends including straight friends:

'If I had grown up in a heavily gay community I think I would probably be one of those real politically correct screaming homosexuals, who are fighting for rights and things, that really do wind me up...they create a bad name; they shout for rights but are still asking to be integrated...by standing up and screaming you're segregating yourselves by making yourselves a separate group rather than just getting on with it...Why make a point? I sleep with men...it's not in my face so why should it be in your face?'

Gareth disassociates himself from the gay scene altogether which he experiences as 'bitchy, very judgmental and selfish' although he does feel that it can also act as a comfort blanket for some people who might not have support from their friends and families. He feels that everyone has got their own opinion of what the gay community is and for him it is quite negative 'like a group of individuals who have segregated themselves even more'.

### *Diagnosis*

At the time of his diagnosis, Gareth was working at a Nursing Home. He had a sore throat, then developed 'flu-like symptoms and eventually couldn't swallow. When he was admitted to hospital he was put on a drip. He was advised to have an HIV test and when he came back positive he was shocked but not that surprised. It was his second HIV test - he had a negative result in 1990; 'I was destined to get it, just later rather than sooner'.

Gareth became very depressed, largely because he was so ill and only recovered very slowly. Because he was diagnosed in a hospital in a low prevalence area, he was a 'novelty' and was 'pestered' by counsellors he didn't want to see and didn't want to talk to. They all wanted him to focus on the fact that he might still be healthy in 10 years



time when 'I don't even think about next week' and actually all he could think about was how ill he felt at that moment. It took him well over a year to recover and suffered from chronic fatigue, and because he was 'rattling around the house all day', he felt more depressed.

### *Telling people*

When Gareth was diagnosed he made a list of people he felt comfortable to tell and stuck to it. He only told colleagues he was already friends with; in the area where he was living and working 'it was bad enough that I was gay'. When he decided to go back into nursing he checked before telling the hospital that he couldn't be discriminated against, but he still won't be allowed to carry out invasive procedures. He has told people who he believes wouldn't run away and wouldn't 'go blabbing it around'. It is an issue of trust; he had one friend who he decided not to tell but who had assumed he was positive, got drunk and told people anyway.

### *Treatment*

Gareth transferred his treatment to a London hospital which he compares very favourably to the local hospital; 'it was a completely different world...they were all geared up' and he currently goes to the Clinic every 6 months.

He did take combination therapy but experienced severe sickness and diarrhoea. He was taking about 26 tablets a day and they were dominating his life. He would start again if his blood counts became poor and if the side effects were manageable.

### *Attitude*

Gareth says HIV isn't really there for him because he's choosing for it not be there as a limiting factor: 'It's a part of me, but not a major part of me...out of sight out of mind'. After he was diagnosed he got a lot of written literature to ensure that he was fully informed but he felt no need to ring a helpline and he feels no need to meet other positive people because he's got his own friends and because HIV is not affecting him detrimentally.

'I don't think you can spend your life worrying about what you should have done and what you could have done and having regrets and stuff because what's done is done and can't be changed. ..I believe in fate to a certain extent...everything happens for a reason...All the negative things I try to turn into positives...I try not to have regrets...

...I nearly died, I was so poorly...and I'm still suffering from the aftershocks of it, but I just put it in a box...which I'm quite fortunate to be able to do...I tend to box up my life into segments...everything that's happened has shaped you as an individual and they've happened for a reason, but I don't see the point of dredging up everything for the sake of dredging it up and causing more torment'.

### *Going back to work*

Gareth was on Incapacity Benefit for two years and has only been able to work at all in the last three months. He decided that prior to going back to nursing full-time he would work for an agency which would get him back into a work routine and lift his confidence. The work has been slow in picking up and from being very well off on a reasonable level of benefit he has earned £44 in the last 2 months as well as being taken off housing benefit. He has had to rely financially on Stefan.

Gareth feels he is not as healthy as he was but he feels he will be able to manage going back into nursing, and he feels that if he is mentally stimulated and enjoying the work environment then he will find the energy to do the hours. It is only in the decision about going back to work that HIV has come to the forefront:

'I've not only got to prove myself as a person, as a nurse, I've got to prove myself with my health, because I'm HIV+ I need to prove that it won't affect me' and there is a constant background worry that in some way it will count against him.

Gareth is also aware that some people at work will be prejudiced; he remembers someone on a previous training course who said that everyone with HIV should be put in a field and shot. Gareth's approach to opinions like these is to ignore them as much as possible:

'I used to be so sensitive but now I just let things wash over me...I don't argue any more and tend not to shout. If it affects me, fine, if it doesn't affect me, wonderful...you just upset yourself more than you upset them.'

### *Health*

Gareth is conscious of his health, but not perhaps as much as he feels he should be; he doesn't do as much exercise as he would like, he feels he drinks and smokes too much, although he eats reasonably healthily.

In terms of his mental health, Gareth says 'I think I've always suffered from depression on and off all my life, I think...it's always going to be there and it's something I've learnt to live with'. He feels going back to work is one thing which will help to keep the depression at bay. The depression coincided with the HIV and the HIV certainly fed the depression. Gareth says that he went along with it for a long time and went to see a psychiatrist whom he found useless; he had 15 minute sessions and the psychiatrist didn't listen to him, he was simply given pills.

'I got so cross one day. I thought bugger it and I simply pulled myself together, it was really quite bizarre'. He gradually weaned himself off the tablets which was very hard; he experienced head spins, panic attacks and palpitations - 'my body needed them'. Now Gareth says that depression doesn't frighten him, 'I've been there'. He is surprised looking back at the change; 'one year ago I was just a nonperson, and it's been my own doing, plus support from friends'.

### *Spiritual beliefs*

Gareth has no spiritual beliefs 'You just die and your body shuts down. That's it'. Through his work he has seen people die and he thinks that people's beliefs in life after death are to make people feel better about dying. 'I'm 32...I'd like to think I'm still immortal'; he feels that he, and many of his friends, have no concept of death at this age; it simply isn't something he cares to address at the moment, 'I'm comfortable with death but it's not something that's affecting me personally at the moment' and it certainly isn't something he worries about.

### *Moving to London*

'Getting out of Surrey was the best thing I've ever done...London is the most fantastic place to live...you can choose to be anonymous if you wish or you can have the closeness of your neighbours and say hello to people if you want to. Gareth really appreciates the diversity of London which feels so 'normal' compared with where he grew up; 'London's normal - normal people doing normal things'

Gareth and Stefan have recently moved into their house in South East London and Gareth is really happy, 'it's quiet but not deathly quiet, it's well connected to the centre and there is always life going on'.

### *Relationships and Friendships*

Gareth says that Stefan's approach is very logical and he is quite a 'don't be silly, pull yourself together' sort of person. Gareth relies on his friends as well as Stefan for emotional support. Stefan doesn't tend to talk about how he feels and for both of them HIV is not at the forefront of their minds.

### *Daily life*

Gareth doesn't have any set routine. He will get up at around 8am with Stefan and make his lunch and then he might watch TV and do nothing, work in the garden, he might have a shift through the nursing agency, he might meet up with his sister and her children or with friends. In terms of his state of mind 'it's very black and white - good days are when things go right and bad days are when things go wrong.'

The positive things in his life currently include the fact that he is working again; everywhere he has worked through the agency he has been offered a job and that gives him the most tremendous buzz. His friends are also very important to him 'and being here with [Stefan]...when he's not whingeing about work and shouting around the house', and his niece and nephew telling him that they love him as soon as he walks in the door is 'a guaranteed lift'.

### *The future*

Gareth says that 'looking to next week is quite a clairvoyancy trip' so he has not set ideas about the future although he will probably stay in London, and will probably stay in the same house for the next 10-15 years. He is also thinking three years ahead to some extent because that is the duration of his nursing training. He and Stefan think they might want to move out of London when they get older and want a slower pace of life and they might retire by the sea.

## **Participant 17 - David**

David is a 40 year old man who was born in London and lives in the East End. He was diagnosed in 1997 in London and is still in good health.

### *Growing up*

David can't remember clearly when he first felt that he was gay and those feelings at first were complicated. He must have been about 14, but he didn't actually realise it and acknowledge it in himself until he was in his 20s. It was quite a long process and painful in the sense of disturbing. His upbringing was strict, his parents were a lot older and he had a sense that something was not quite right, a sense of being different which he couldn't identify.

'You're always normal because that is what you are, nothing to compare it with'

Over time he gradually realised what was he himself rather than what they wanted him to be. He had relationships with men before identifying as gay, 'which probably had quite an influence!' From quite a young age he went cottaging and this escalated, 'made me put two and two together.'

### *Cottaging*

David went cottaging regularly, which was made even more complicated from his early 20s because by then he was in the police. He would only take the risk of cottaging 'under the influence of a considerable amount of alcohol' and also he didn't go to the area he covered as an officer.

David says that at the time there were many more cottages and although there was a perception that they were full of police you had to be very unlucky to be caught, there were fewer police on the streets than most people realised...'But there was a risk and this contributed to leaving the police, it was a conscious choice - if it was going to be either this or that, I knew which it was going to be.' So David left the police after 10 years, about 10 years ago.

David didn't Come Out in police; it would have been extremely difficult, and would have conflicted 'with an image which was false, but the image was I was strict, hard, straight down on people, more of a job than they were. The image was passed on like Chinese whispers. If I'd Come Out that I was gay, the feminine type perception of it would have made it very difficult.'

### *Diagnosis*

David had had a couple of long-term relationships. When he split up from the second one, in 1994, he started to get unexplained skin rashes etc.

After numerous visits to the doctors and numerous theories as to the cause of these skin problems, he then went to the doctor with a swollen knuckle thinking it might be arthritis. The doctor took blood tests and rang him back at 10.30 that night: the platelet count in the blood sample was about 35 and the consultant wanted to see him within 48 hours. David says that the second count was 100, so they got quite confused about it. Eventually they did a mass of blood tests. After this David was basically told

that it was worth doing the tests because they found out what it was and then they skipped on to something else. 'Before I went for the blood tests HIV had got into my mind...are they testing for this and I 'phoned the THT Helpline. So the moment they said we think we know what it is, it seemed a pretty good pointer.'

David put this to the back of his mind, but then, not long after, 'I bumped into one of my long-term ex-s who turned round to me in the pub and said 'I'm HIV+ and you infected me', and it was at that point I decided to go and get the test.

David found going for the test itself was relatively minor. The hardest part of it was the waiting between the test and result; he was on holiday from work and spent four days down in Brighton on his own 'which I quite often do. But of course, you go down there and you've got nothing to think about.'

'When I sat down and the counsellor said, 'I'm afraid I've got some bad news for you', the first thing that went through my mind was 'Oh shit! She hasn't got the results yet!' We then went on to a discussion about techniques of telling people, because obviously in the police you have to do that sort of thing...I had a cup of tea and went back to work...I was deputy manager of a shopping centre with security guards underneath me, I was sitting down having a cup of tea, one of them walks past, 'What did the doctor say? How long have you got left? 6 months?' ...I think my answer was something like go away...it wasn't too bad, you just think 'you idiot, if only you knew what you'd said.000'

In quite a lot of ways I was almost glad [to be diagnosed]. I'd had the various problems like the platelets and my skin had got so bad it was waking me up at night, I was scratching so much I'd start to bleed. So on the one hand I knew where it was coming from. Also, for most gay people, particularly in the '80's, or if you'd been about in the '80's or early '90's, AIDS was the big fear. It seems a bit sick to say, but once you'd got it, you didn't have to worry about catching it...quite funny.'

### *Support services*

David says that in the last year or two before he was diagnosed he got to know other HIV+ people. He also feels he was fortunate to be diagnosed at the time he was, he feels that being diagnosed 10 years earlier would have been like being diagnosed with death in fact it was hardly worth being tested then because there were no treatments. Now he feels there are 'more treatments and more people who are open about being positive who you can talk to which I personally feel is the most important thing, it's not counselling or back-up services, it's access to other positive people in a so-called comfortable environment...I've found it myself straight away, it's where you're comfortable...you know 'Waiting for Godo'? Well I nicknamed the \_\_\_\_\_ Centre 'Waiting for Death' because everybody sat around like they were in a library...I really don't want to be like this!...I knew a couple of people outside and outside they were fine, what I thought was fine, but in there they were sitting like they were waiting for a knock on the door...places are just too quiet, there's no life in them'

'Even though it's nice in here [names another support organisation] it's still cold and sterile. What's missing is the Youth Club type atmosphere, the pub atmosphere, but you're not going to get that because people still view people with HIV as dying, therefore it should be a quiet area. That's fine for the people who need that, it's

certainly not for me. I think services have missed out on the vast number of people like me, but the argument in reverse is you could say I didn't really need it. The problem is people twist themselves, relatively minor problems get escalated, it encourages people to be worse to get the most out of the system.'

### *Finances*

David says he was lucky because he qualified for Disability Living Allowance under the Special Rules. 'The thrombocytopaenia counts as a major illness, my CD4 count was 130-200 and my VL was 180,000. I could never have kept a straight face if I'd had to answer all those questions...I get night sweats around May when I haven't taken the Winter duvet off, I get out of breath because I smoke too much!'

### *Work*

At the time of David's diagnosis he was in the process of buying a house with a view to renting out some of the rooms and eventually giving up work. The combination of the shock of his diagnosis and the demands of the work on the house persuaded him to go off sick and in the end he was able to negotiate a generous settlement. 'I'd planned to stop anyway, I just stopped 6 months earlier and got a few grand extra!'

One of the major things David finds is filling in the time, especially as he is quite active. On the other hand, either because of the HIV or the combination therapy he doesn't feel he would be able to do a full 8 hour day.

He feels it must be difficult for people who were busy and everything stops dead, and this he feels is possibly where the organisations do harm; people need something to do that isn't focused on the disease whereas the drop-in centres where people naturally congregate focus exclusively on HIV.

David has decided to go back to being a student and is studying criminology in East London:

'it's quite interesting, quite funny... It's quite a mature course, although all of them are younger than me, although they don't always realise it! What confuses them...is my attitude...what are you going to do with this degree...nothing...Basically it's interesting and it's something to do, it's a challenge.'

David's initial decision to be open about his status was based on the gay London scene; perhaps as a result of his experiences in the country (see below), he has decided not to be out at University. Two lecturers know, 'I don't think either of them will have mentioned it to anyone else. I think they're more frightened because they don't know what to do and don't know what to say anyway.'

Studying might not be an indefinite option but David says he does not think he would be able to work full-time and he would find voluntary work very frustrating: 'I'm too ambitious. There's no such thing as a friendly game for me, you can be friendly and smile while I stand on your foot and nick your cards! Most organisations I've worked in are very efficient and most voluntary organisations are extremely inefficient.'

### *Living in London*

David had an affair with someone he met on holiday in Gran Canaria who lives in the country. Up until this point, in London, David had decided to be open about his diagnosis. Then it came up in conversation with one of his partner's friends and it was clearly a major issue:

'It made me realise the difference between what was normal in London and was normal, or what wasn't normal, outside. In London it's 'Oh, sorry to hear that, do you want another drink?' whereas outside it's 'Oh shit - he's got AIDS!' It makes you realise how different it is...I was quite shocked...

...I ended up living with this particular person...the closest street was about 5 miles away. I ended up living there for about 5 months. There's no gay scene out there. There was one drop-in centre I went to, it was really weird. It covered a county and a half. They had this policy there...the idea was that anyone could be anyone...it was so obvious, there would be 4 ...middle-aged housewives who've got nothing better to do with their time than sit there fussing round making sandwiches and tea and coffee. There were probably 2 or 3 other people just sitting round. The use of places like this are the connections with other positive people, but in a setting like that where you're pretending it's not happened - ...really bizarre'

### *HIV and relationships*

David has a general policy of telling a sexual partner his status from the start: 'If I'm taking someone back, or I'm going back with someone, I'll tell them, usually before we get indoors, so if they want to say 'no', well OK. If you wait till someone's indoors, the pressure is on them.'

He says the attitude of his ex-partner (the one who lived in the country) was very naïve: 'it would be a case of 'talk to me, anything you want to' and the moment you did it would be...'what's on tele?' I'm quite used to dealing with things...I'm harder and more able to take things on board than most people...I suppose he couldn't deal with it, but was prepared to ignore it, and there seemed no point in trying to force it. It does raise issues...I can understand people who are positive saying they won't go out with somebody who isn't positive.'

David would like a relationship if the right person came along but the biggest difficulty is finding someone who's on the same wavelength; 'I think that's unlikely, in terms of mental discipline as much as anything else...mental discipline and misbehaviour - combine the two!' He can't bear people to be unreliable and equally it wouldn't work if someone had a problem about his status.

'I'm not going to waste my time. If someone comes up to me and says they want a relationship, they're in love, I'll say 'sorry, I want a shag 'cos I'm in lust!'

'Another problem I have is that I generally go for people who are quite a bit younger than me.. Quite often they're not in a stable job or in a job at all, I'm in a much better position. They end up convincing themselves they're in love with me and you wonder how much is it me and how much is it the lifestyle and how much is it being able to go out when we want and where we want. It's when they don't know the difference.'

### *Contact with other positive people:*

'I think there's more openness, more willingness to discuss things, than with a professional, particularly one you don't know ...if you listen to two positive people, they take the piss out of the professionals - How do I *feel* about this? How the fuck do you think I feel about this! I'm pissed off with it, I don't like it! With professionals there's a tendency to...try and pull things out of people, which is possibly where you get the situation in the Centres where people are depressed when they're in them. People want to suppress their feelings...[professionals' attitudes] differentiate, it pulls people out and makes it a major part of them. It focuses attention on it...it almost becomes you...If you go to the pub and chat about it, it's part of your social scene.'

### *Place of HIV in his life*

'...It's a part of my life which has a lot of influence...In one sense it makes me concentrate more on what am I going to do, what am I doing, in terms of plans...you'd go for enjoyment rather than long-term planning'

### *Health*

For two years David's health was very good, his Viral Load undetectable and he had one change of combination therapy when his Viral Load went up. He was on prophylactic septrin and stopped it a year ago. However, this was 'a nightmare'; in the next three months he had 2-3 chest infections; he had an anti-pneumonia vaccination but got common pneumonia (not pcp). The doctors had no idea why he got this. He's now gone back onto septrin even though his CD4 count is over the level where pcp is a risk. 'While I was off septrin I had continuous bad coughs, bad enough to affect which pub I went to, I'd go to G.A.Y. because it's loud there I could cough and no-one would notice!'

The pneumonia has been the only major health problem David has experienced and it was 'quite a kick in the teeth...Looking back on it, it was quite funny. I'd had a pain in the chest on Monday, by the Friday I was much worse and rang the hospital. They said, breath in as hard as you can (He makes a spluttery noise) Is that it? You'd better come in. Then [I saw] the staff nurse who I used to go out drinking with and insist on marching from one pub to the next...He said 'Is that the quickest you can walk?' I got this x-ray and it was classic symptoms of pneumonia.'

As soon as he was admitted he started to feel better, but there was still an anxiety about why he got it in the first place. 'My CD4 count was 400-450, double what it had been, an undetectable Viral Load...why?...Until I managed to get the message through to my brain that it's an air-borne virus - nothing to do with HIV...anyone could get it; it's a virus that you catch, and you either cough it up in time or you don't. But you start thinking, if I can get that, I can get anything - what relevance are CD4 counts and Viral Loads if that happens?'

'I would call myself reasonably healthy. The only thing is I get tired after a few hours of doing something. It's difficult to tell if it's the HIV or simply getting older! One of the difficult things is telling, is it normal, is it not?'

In terms of his mental health, David says he felt very low after the bout of pneumonia 'Fortunately I realised it for myself and eventually managed to pull round from it...it's really mental discipline, you've got to ignore it'



### *Medical services*

David likes the fact that the doctor and many of the clinic staff are gay,

'I kept wanting to say to the doctor about going back on septrin but each appointment I'd got distracted by something else, so the next appointment I decided to go out the night before and smoke a lot and so I'd cough a lot in the morning. So I went to G.A.Y. and got back about 4 in the morning. And I was coughing a lot, and the doctor said 'had a good night last night?' at which point I went a bit red and said, 'Is it that obvious?' and he said, 'No, I was at the club as well, I saw you!' I like him. He's gay so we have quite a lot of common ground. Quite a lot of the staff...go to my local pub'.

### *Complementary therapy*

David had some massage when he was first diagnosed and found it relaxing but in general is sceptical about complementary therapies:

'perhaps I'm being unkind, but I think it's more about people wanting to do something, I don't think there's any real connection. It's very nice but it's not really doing anything for me.'

### *Combination therapy*

David's first combination included DdI 'which was a nightmare', 'DdI tablets are a bit like trebor mints in size, you crush them and drink them with water or apple juice. But it doesn't mix in, it just floats on top. It was like drinking chalk crushed up. I went back to the hospital and said, 'I can't do this' and they just said, 'Try this one instead'. About a third of people can't do it. If I had known I would have come in quicker and not felt so guilty about not being able to do it.'

He was started on a dual combination with a view to adding a third once he was settled but his viral load went from 180,000 to undetectable on a dual combination in under 6 weeks, so he decided to stay on a dual combination. He might well become resistant to AZT more quickly but he still hasn't taken any protease inhibitors so he has several future options.

### *Pubs/clubs*

David goes to the pub most nights, with the exceptions of the night before he's got to be at University. In fact part of the reason why he's doing the course is to give him something else to do so that he doesn't go out every night of the week, 'I'm the sort of person who would keep going out, even though they felt ill from going out so much, almost habitually, unless there was something to keep me in.'

'I'm the last part of a generation that was a pub generation before the time of taking ecstasy...Part of it is looking around to see if there's anyone I can cop-off with. And I don't mean looking for someone I can fall in love with...It's a combination of drink, sex and probably last on the list someone to talk to. I'm a bad boy...I decide where to go by what's available on the night. I don't like the smaller places, I've probably got too much of a bad reputation there, I go to larger places. The smallest place I'll go will have a 2-300 capacity, the larger places will have a 2,000 capacity; those are the types of places I'll like. Not so much the anonymity, it's if you go to a small pub you'll see

the same faces week in week out, you might as well go down to the local and see the same faces there. I like to see a turn over of people. It's nice to see friends but it's nice to have different faces - the new possibilities!...

...I go to the extremes, I go to G.A.Y....most gay people would describe it as a fluffy pub. Disco type place. I also go to the Block which is a dress code type place. They have an underwear night. And anywhere in the middle!...

...It depends what mood I'm in, what I'm looking for. In a nutshell, if I go to The Block you basically get sex but you might not like the people you have it with, if you go to G.A.Y. you're not guaranteed to but you're more likely to have more of what you like. Other places I don't go to so often is because of their security policy. There is a tendency now in some of the pubs beyond having people on the door, they check things like the toilets and throw people out if there are two in a cubicle. Heaven has a policy now where if they find 2 in a cubicle, they detain them and search them for drugs. .. I can understand their logic but it's not a good way of doing it, and that influences where I go. Also Heaven now employ people to walk around to make sure people are behaving themselves on the dance floor. What made it worse, the last place that did this was a place called The Tube, I must admit I do misbehave in places sometimes, just slightly, but it so happened that the same security guy is also the doorman at the Block where I go and he knows me from there. So not only is there a security person who's wandering around but it's someone who knows me and knows what I'm like! I'm wary because I'm basically a bad boy. I go to places and do what I want to do, if it doesn't conform with what they want, well, it's your choice, kick me out, but I'm a piss-head and spend a lot of money in a pub, so they sort of say 'If it was anyone else we'd throw you out and tell you you were barred and you can't come back, but we'll overlook it this once!'

### *Sexual relationships*

Since his diagnosis David is perhaps more insistent about using a condom but in fact he was pretty insistent beforehand anyway.

'I tend to sometimes play along with it especially with people who are a bit naïve, who say 'I'm alright and you look alright so we don't need to and I sort of go along with it and stop about 2 seconds beforehand and say 'By the way, you were wrong, where would you be in 10 minutes time if I hadn't told you. Just really for impact.'

### *Family*

David hasn't spoken to his parents for 10 years. He lived in Spain for a time and when he got back he never got in touch with them again:

'I don't really know why, but I didn't want to and despite many people trying to persuade me otherwise, if I got back in touch with them, I would just want to do the same thing again, so there seemed little point. I should think they'll die in the next 10 years. They must be around 80. They wouldn't understand half the things I say anyway.'

He has a sister who is married with two children. He discussed with her the fact that he was going to cease any contact with his parents but said he wanted to keep in touch with her and the children. Her response was that it was going to be impossible to

explain this to the children and he would have to make a total break. He sometimes considers getting back in touch with her now, although he would have to decide if he would tell her about his status.

'Even now I can't actually say why I cut myself off from my parents, I've no regrets about doing it, I think it was the right thing to do, but I couldn't tell you why. How can I explain it to my nephews? Maybe my sister could tell them, but I couldn't.

'I'm not an insurance policy for [my parents]. If they wanted an insurance policy they should have taken one out. No, I'm not going to look after them. I'm not going to look after them because I have to, if I do it's because I want to and I didn't choose to be born...that's why I don't feel guilty about not being there...They used to go on about that sort of thing.'

### *Living in the East End*

'That's the area I come from, born and brought up in ...It's too quiet outside London. ..I feel comfortable in the area although a lot of people aren't. I know the things that go on - OK, people get killed, people get beaten up, it's not something new. If it happens to you it's frightening but at the end of the day you could move out to anywhere and still the same thing could happen. ..If you're walking down the road and there's a group on the other side of the road, it's picking up whether there's a danger or not, sometimes you might cross over or turn down a street to get away.'

David hasn't experienced any overt homophobia from his neighbours:

'They must know. I don't really speak to them that much, but the fact I've got three gay lodgers gives a bit of an indication! There's no females or kids, it's just males going in and out of the house, including any trade or friends. I think they've got a pretty good idea...There are certainly one or two who'd like to say something but won't - they don't really have the grounds to, nothing they can say. I could be totally wrong but you pick up they don't like it. Probably they think it's totally disgusting and I'd say it's none of your business. I don't really care, as long as it doesn't affect me or the people who live in my house. I'm quite happy to ignore them when we walk down the street if they ignore me.'

David has a policy of having gay lodgers. He needs to rent out rooms for the money and sometimes he doesn't like having to share his living space but at the same time 'if you're not working, you can get very lonely if you don't go out. Say you have one night in - that's close on 48 hours that you might not speak to anyone. You go into a supermarket and someone says '£2.50' and that's your conversation for the day. People say you can ring a friend, but I'm not that sort of person, I can't see the point of ringing up someone to talk if you've got nothing to say.'

He is currently planning a loft conversion which will give him a separate lounge and mini-kitchen. At the moment he has his computer, bed, television, shower, sink, 'fridge, kettle, clothes, scanner, printer, all in his bedroom - very squashed!

### *Long-term future*

After David has finished his degree he will probably go straight on to do a Masters.

'I don't think I'm in much of a position to be able to plan more than 3-5 years. I've been on this combination two years and combinations tend to be effective 18 months overall. I take my tablets very religiously but even so, I'm in a period of grace with my current combination, there's only really one front-line combination left - the protease inhibitors, so if that's 18 months, you get another 6 months for a change-over period, another 6 months for a fail period - say 3 years, then I'm on recycled options or hoping new drugs have come out. Working on 3-5 more years would be - I wouldn't say unrealistic - but optimistic. It's a rolling buffer, it's a rolling 3-5 years...At the moment it's fine. I'm saying three to five years. Unless something changes, in a year's time I'll still be saying three to five years, so then it's 4-6 years at the moment.

'My attitude towards treatments is that I'm looking at 3-5 years that I'm OK, maybe in that time new drugs will come on the market so extend that further, hopefully over the course of that time there'll be, if not a cure, then life-long control will be established, and I think that's a major thing for optimism. It's not you're waiting to die, it's how long am I going to live...If that hope was taken away from people, then you'd get a different attitude...people like me who are not on their first combination are saying there is quite a lot of hope.'

#### *Religious beliefs:*

'If there is I'll find out later! I'm not religious but if you can help someone then help them, if you can't, don't do anything bad to them...If there is a God he can't slag me off too much, I haven't been that bad!'

#### *Daily life*

David's day depends if he's at university. He might go in to university or stay at home to work. If his day is free he's usually gone out the night before, 'got back at 5 or 6 o'clock not too sober, in which case my day would be sleeping till about 1 o'clock and lying in bed suffering for the next 5 hours until I get up and have something to eat. Or I might get up at 8 o'clock, go to a lecture and come home and do some work and some reading - it varies between those two extremes...I have set routines but it depends on which set I pick.'

David is still very careful about sticking to his medication regime:

'The original combination was much more difficult, because one was twice a day and one was three times a day so in actual fact I took tablets 4 times a day 9, 5, 9, 2.o'clock, whereas now it's twice a day - 11 o'clock, which is just before I'd go out of a night time. Whatever time I take my drugs, I wake up at that time...I always wake up between 10.30 and 11.30...It's a case of, I want to carry on living but I need to take these to do it. There's no point taking them and missing half of them.

#### *Attitude*

David makes a joke of much of life; he calls his humour 'police humour...it rubs off with the HIV. Being in the police for 10 years, you see a lot of things you don't like and you have to deal with them...you use humour...it makes it a lot easier to get on with your life...it's something you can't teach people.

## **Participant 18 - Tom**

Tom is a 52 year old man who was born in Lancashire but now lives in London. He was diagnosed in 1986 and after a period of not working has just started back at work as a nurse.

### *Comparing HIV services in London and the north*

Tom begins his story telling me about his move to London from a city in the north of England where he and his then partner were working as nurses - a move which was largely motivated by the improved work opportunities in London. When a couple of years later his partner returned north, rumours had gone round that Tom had died, Tom says that 'tittle tattle goes on' in small places whereas in London, 'if you want to be anonymous you can be'.

He compares HIV services in London to the north of England where there are fewer centres. He spent some time as a volunteer in a local HIV agency where he spent most of his time 'folding red ribbons and drinking coffee', it was run by well meaning people but they weren't qualified, whereas services in London are more comprehensive and more professionally run.

One of the most important things that was going on in Tom's life at the time of the interviews was his decision to go back to work as a nurse. This involved coming off Incapacity Benefit and he received comprehensive advice about the implications of this decision from a local HIV organisation - advice which he is sure he would not have been able to access up north.

### *Leaving work and the decision to go back*

Tom had been working in a London hospital as a nurse when he had to take three weeks off with a chest infection which was unrelated to his HIV. Nevertheless he decided to take the opportunity to retire - at the time he was the twenty second male nurse to retire as a result of the virus. He had a good retirement package from the hospital but 'what you don't realise 3 years down the road is how bored you get, you need the stimulation' Tom isn't 'a pubber and clubber'; he says that some people he knows are happy to finish work, get benefits and go raving but he's never been that type of person. He also thinks that people retire and within 5 years they're dead because that purpose to getting up in the morning has gone, nothing to do with AIDS. He questions now whether it was a good idea to have retired from work in the first place but given the circumstances at the time, it seemed the most sensible choice available to him.

Tom found himself struggling to fill his day. He did two courses on counselling and complementary therapies and after these finished he decided to go back to work as an agency nurse. This is a big drop in responsibility but Tom is really enjoying it and appreciates the reduced pressure. He has felt a bit rusty at first and has had to get to grips with computer held records but is managing very well. Whilst he was not working it was easier for him to look after himself - through going swimming, looking after his diet etc. and he has decided only to work late shifts so that he doesn't have early mornings to deal with.

When Tom made the decision to go back to work he contacted the Royal College of Nursing and UKCC to ask them what implications his HIV status might have on his career. He was told that he could not work in operating theatres, ITU, coronary care or with children, although, rather paradoxically, he is allowed to work in a surgical ward.

Tom talked to a worker who is also a friend at an HIV agency who telephoned nursing agencies to make a general query about their HIV policy. The first agency he rang simply laughed down the 'phone until they realised that they were talking to a well known professional in the field and then they quickly said that they were revising their policy in this area. On the other hand another agency sent their policy which stated that he had a responsibility to declare his status and stipulated areas in which he would not be able to work. Tom says that this particular agency have been careful to give him relatively easy work at first as he has had a career gap of three years. On the other hand, on his sixth shift, he was the most senior person on that ward, so he is now working at a higher level.

#### *Other work opportunities*

Tom hopes to get work as a therapist. He is currently doing massage on a voluntary basis and is advertising in the gay press as a massage therapist. He gets about two 'genuine responses' a week.

Tom says that London has given him more opportunities to continue his education and the culture in London helps him to believe he's not a right off. He has, for example, been able to do a computer course which has proved to be invaluable on his return to work. On the other hand, he still feels that the London HIV centres tend to promote a culture which isn't always helpful:

'The same people are there every morning at 10.00, they drink coffee and talk about where they'd been the night before and have lunch there, they're in their 30s and that's not good for anybody at the end of the day. The intention is to combat isolation but they promote a culture of not pushing people, if I mention that I'm studying or want to go back to work, they don't want to know because it actually challenges them.'

Tom says in some ways it is a shame that the HIV services in London are being cut but in other ways he questions whether they are needed any more. He sometimes wonders whether it is right that HIV gets privileged over other health conditions in terms of the services available to people.

#### *The importance of work*

Tom is very clear that working plays a vital role in his life:

'I need the stimulation, the purpose in getting up, the interaction with colleagues, the laugh you have...the benefits keep you to a reasonable standard of living but there's the idea of earning the money rather than it being given to you...Everyone needs goals and aims, regardless of age, people give up...when they haven't got a purpose...If you've got a mission for 5 years it also means that you think you're going to be here in 5 year's time...It might not suit everybody but more and more people are thinking of doing something constructive...

...In the 3 year's I've been off, Bank Holidays haven't had any meaning. When you're not working, you don't know the date, working defines the day...you're not an active member of society...at the end of the day I'm filling my time in, I'm not actually doing anything constructive...Now I'm qualified as a therapist and back to work I have got something to offer.'

Tom recognises that his benefit situation (he was only ever on Incapacity Benefit) and the fact he had a profession to return to meant that he was losing less in coming off benefit.

Tom spent some time working as a nurse up north and he feels that things don't seem to have changed at all outside London in terms of people's attitudes, with secrecy, fear and paranoia still endemic. He chose not to declare his status when he was up north whereas he has had no problem in London. Tom doesn't understand the anxiety about nurses with HIV:

'There are media scandals around operating theatres and everybody's hyped up about children, I can't see logic behind it, I can work on a ward where people have had large bowel surgery, I can't see the difference, but this is the ruling from the UKCC.'

### *Counselling*

Tom has had counselling which he believes he would not have been offered up north and which has proved invaluable to him. After Tom and his partner split up, he got a social work assessment and was offered counselling. He says his counsellor 'has been the most influential person in my life'. They discussed his relationship and then started dealing 'with issues about me as a person'. He has only recently stopped counselling after two and a half years. One of the ways in which counselling has challenged Tom is around his own self-image. As he approached his 50th birthday he was feeling very negative about what he had to offer a potential partner and his counsellor encouraged him to create for himself a much more positive idea of himself; 'she gave me back my self worth, my purpose in life...it made me think about my role and what I want.'

### *Family background*

Tom never saw any emotion between his mother and father. He was close to his mother but his father, a butcher, was very macho. He had a violent temper and Tom was scared of him. Whenever his father tried to touch his mother, she would fold her arms across her body, across her heart, closing herself off from him. It is only very recently that Tom has discovered that his mother had an affair with an American soldier during the war and had a child by him, a little girl, who was given away at birth. The whole family had kept this quiet for fifty years and Tom only found this out after his mother had died.

### *Coming out as gay*

Tom got married in 1972 in the north of England, so in a particular historical and cultural context. He and his ex-wife were initially school friends. He always denied he was gay although he was having sex with men in cruising areas and cottages. He had been going out with the same girl for seven years and they were engaged but it never occurred to Tom that they were going to get married, but then Tom came under pressure 'and all of a sudden you're on this conveyor belt'. He got married not

accepting his sexuality - he decided it was his private life, as it was for the other married men he saw at the cruising areas, 'I think a lot of people led a double life in those days'. Tom's job involved travel which also fitted in well with his lifestyle.

Tom came down to London to stay with his brother and 'saw a guy who looked like Cat Stevens'. He ended up talking to him, going back to his place, they went to bed and later went out for a meal and he stayed the night. 'It was the first time I'd ever slept with a man...I was very in awe of what had happened.'

On his return, he ended up telling his wife that he had met a man. Once he had said it, the weight was off his shoulders and it was in many ways a relief. Tom and his wife agreed that he would live in London for 6 months as a trial period. 'I don't really think I sat down and thought what I was doing, who I was hurting.'

Tom's eldest brother only talked to him once about it when he offered to pay for aversion therapy - either shock treatments or injections of an emetic. That was still an option in those days. 'I remember saying, 'but I like going with men' and the look on his face!' At the time Tom was very angry but now he realises that it was well meant.

Tom's mother and father took him to the doctor and, although he was married and 22, the medical report was returned to his parents. The medical report said that he seemed happy and settled with his sexuality. The only time his father mentioned it was when he asked him (rhetorically) what Tom thought *he* had done during the war when he was stationed in Egypt.

After 6 months, Tom's wife came down to live with him and they made a compromise which allowed Tom to have sex with men. After a year they moved back up north, but after a while, Tom wanted to live by himself and have the freedom to do what he wanted. In the end Tom asked for a separation.

'I know I caused her a lot of pain...but I didn't really think what I was doing...I treated life very lightheartedly.'

'I believe that what goes around comes around, and when my relationship broke up [see below], I believe that a lot happened to me as it happened to [my ex-wife]'

Within about six months, Tom met Tony and they started living together but they were still careful not to broadcast that they were a couple.

'When you come out...you get a little outrageous...you want everybody to know. Now, if I meet people, I want to get to know them before I tell them anything about me...there's a limit to what I reveal about myself, and it's the same with my HIV status. Why should I tell anyone about my sexual orientation or my HIV status if I'm never likely to see them again?'

#### *Being positive as a positive gay man*

'I feel very much at ease living as a gay man and as a positive gay man. In fact, I don't actually know, if I had the choice, if I wouldn't be positive again, mainly because I would not have the same number of friends that I have now...most of my friends are positive, I've got a lot more friends. It's made me see what's important in life, it made



me re-evaluate my life, made me think who's important, who are the good friends, what do I want out of life, what do I want to achieve... I most probably would have just carried on being a nurse without thinking where I was going.'

A couple of years ago, Tom went on a holiday for positive gay men which involved activities like archery, planting trees, building a raft and swimming:

'I never enjoyed a weekend away as much, because I did things I've never done before... Things like that, being positive has given me opportunities.'

Tom recognises that in some ways he has been privileged because of his status, for example he got a grant for his computer because he completed the computer course. He questions whether it is right that he should receive these extra privileges. He realises that the government might well change what subsidies and payments people with HIV receive and feels that there is some truth and justice in this.

### *Diagnosis*

Tom was diagnosed in Amsterdam in December 1986 when AZT was the only treatment option available. He said that at the time there were a lot of 'emaciated AIDS victims' around which was scary but didn't stop him having unprotected sex at the end of the day. At that time he had some brown marks on his arms and he would put felt tip marks around them to see if they grew: 'the fear of not knowing was worse than knowing'. He went to a gay doctor and was tested but hadn't really thought through the implications of getting a positive result, so when he did, he put it right to the back of his mind. 'I went into a total denial for years.' He went for another test in London in 1992, when he actually felt ready to receive the diagnosis.

'...I'm very much the sort of person - I have to know things. I found it far more of a worry before I was diagnosed. When I was diagnosed it was a relief... Being told I was positive, then I could concentrate on getting as much information from people like NAM etc. on conditions, drugs, lifestyle and stuff... I'm the sort of person, I like to plan things, and say, yes this is what I'm going to do... I think it's very important to get diagnosed when you're ready... I don't consider that I'm going to die of AIDS. I'm 52, healthy enough, the only things I'm going to die of are old age and cancer of the lungs because I smoke too much!'

Tom says in some ways it is a shame that services such as recently diagnosed groups weren't in existence when he was diagnosed but he thinks that there was more peer support available. At the time he wanted to get involved with the world of HIV although now he feels the need to distance himself from HIV services - he doesn't feel the need to be involved with positive people any more.

In terms of his blood counts, Tom's health is excellent, with an undetectable viral load for over two years and a CD4 count of 800. He doesn't take social drugs, except for smoking, or drink to excess and he has never had an AIDS defining condition. He has very recently been signed on again as fit for work and come off his benefits. That is now his focus.

Tom cites Elizabeth Kubler-Ross' stages of grieving in terms of adjusting to a positive result; he says that he can see how he has moved through each of these stages, maybe more than once, and now is in a state of acceptance.

#### *Medical services and complementary therapies*

Tom does 'therapy swaps' with other therapists but notices that it is now much harder to access complementary therapies through HIV services which seem to provide more welfare rights advice. He does question anyway why therapies should only be available free to people with HIV when they can benefit all sorts of people.

#### *Relationship*

Tom was in a relationship with Tony for 18 years but Tony was diagnosed after he and Tom split up. Tom describes Tony as refusing to face the reality of his diagnosis - he did not go for a test until his health was severely compromised and he refuses to speak with other HIV positive people. After Tom was diagnosed Tony would never ask him about his hospital appointments 'because by asking me it challenged his situation, he just didn't want to know, as far as getting support there was just none there at all. I got far more support from things like the Men's Group, because there I was meeting people who didn't look emaciated, who were working, who were looking well, and going away for the weekend'

#### *Sexual dysfunction*

A while ago, Tom started to experience sexual dysfunction:

'...just nothing happened at all. You think, what is the point of having a Viral Load and CD4 count if I'm not...It's a bit like when you're not looking for it, more people start coming on to you, well what's the point?'

It transpired that DdI, which was one of his combination tablets, suppresses the production of testosterone but this was not something Tom was told at the time.

'It does your head in, it really does, and there are very few people you can tell about this...I went to the doctor, then went on a very long roll. First to the GU Clinic to have my prostate milked, bloods and urine done, a month for the results. Then sent for cavernogram, one of the most difficult procedures, you go to the X-ray department, they put 2 needles in your penis which gives you an erection. You don't see it because they've got a green plate up, but everybody on the other side of the plate, you've got both male and female...and all you see is the TV screen which is heat, and then you see if it stays up. So you go through all of this to see if there's any mechanical reason why it's not working.'

Tom was then sent to a urologist who suggested that they give him a rubber band and a suction tube.

'I said, 'you're suggesting if I meet someone I just say, give me half an hour whilst I put my suction tube on and try and get an erection...I was so angry I just left. I said 'you can go to Soho and get those, I don't need a urologist to tell me this' and I left.'

As in other areas of his life, Tom found his counsellor to be a great help. She pointed out that his relationship had just ended, his mother had just died and he had just moved house, it was hardly surprising that he couldn't get an erection. Tom also

discussed it with his friend who works in the field and he organised a closed confidential focus group on the issue. Tom felt this was very helpful for those who attended who were all of different ages, some of whom were on HIV drugs and some who were not.

He describes this time as mentally one of the worst, 'feeling like your self worth was like down here because you're just useless, it really did feel like you were useless sexually. You actually go out to meet somebody, you never find them, if you just go out with friends and you're ignoring everybody, all of a sudden people start coming on to you, and it was the same because you were going out and thinking well I'm not looking for anybody because I can't do anything, all of a sudden you've got some really hunky guys giving you the eye and coming on to you, and you think, well you're wasting your time, you're going to be disappointed.'

Tom was prescribed Kavajex injections but he didn't find that they worked. Finally he was prescribed viagra on a private prescription. 'I went off to a well known pub in Islington, I took this tablet and I sat there with this pint, and it said 20 minutes so I'm watching the clock... Yes it did happen, and the feeling that you're back in the running, in the game, was a tremendous boost. I've been out with friends and taken a viagra - [it] gives you the self confidence.'

In combination with the viagra, Tom discussed with his counsellor his desire for an emotional relationship.

'Sometimes I can get an erection and sometimes I can't, and basically it gets down to the emotional feeling you have to perform, put out, not feeling at ease, and if you're comfortable with whoever you're with and it's done say in an erotic passionate way then yes things happen...If you get a failed erection once, or if things don't go right, then it's a problem...if you get a barrier, it's getting over that barrier.'

Tom's two brothers also experience erectile dysfunction and both are also on viagra.

'It's like having that security. I always have a couple of tablets with me in my wallet. You think, if I need them, they're there. I know exactly how long they take to work and I can feel the flush come over...when I'm feeling a little unsure about myself, that's when I take a viagra because I need that boost.'

Again, Tom doesn't think that he would have been able to get viagra if he had been living in the north of England. 'No way would I have got that back up north, I would not have got a doctor who would have listened or understood, never mind all those investigations.'

Tom says that managing disclosing his need for viagra is something he still struggles with:

'A few months ago when I was doing this dating thing, I'd been out for a meal, came back, this guy was OK, because he had come back it was obvious he was going to stay the night, I'd taken the viagra whilst I was making a cup of tea. Then we'd be chatting for ages, I said, 'are you staying?'' and he said 'yeah' and I said, 'let's go to bed' he said, 'I need to take a tablet first'. He was so open, he really impressed me the

fact he was so open. He was positive anyway. He took the tablet, he said, 'do you want to take one, I've got a spare one', I said 'I've already taken one', then I felt guilty because I'd sneaked mine in whereas he was open and said it.'

### *Telling*

Tom says he has a lot more difficulty telling someone his age than his HIV status and he describes gay culture as very ageist.

'Three years ago...I put an advert in Positive Nation being totally honest about my age which then would have been 49. I put down things like sense of humour, honesty, loyalty, no response. Did exactly the same advert and took out the age line and got 7 replies. If you put down 49, you've got a preconceived idea of what someone of 49 looks like...It is a problem... I don't say my age but I slip up and say wireless rather than radio!...The optimum age is 37. If you look through the adverts in Boyz nobody's over 37 in Boyz magazine.'

### *Looking for a relationship?*

'I wouldn't mind a partner if he's the right guy, but not for the sake of having someone sat on the sofa type of thing, being positive is one of the criteria, but also someone late 30s 40s, they've got their head screwed on, I don't want them newly diagnosed or just out of a relationship because they've got a lot of baggage, so I know what I want.'

### *Living alone*

On the whole Tom is happy living on his own. He realised after the relationship with Tony had officially ended that in fact it had in many ways ended after two years, but they had stayed together 'because it's easy, you're tied up with the mortgage the jobs and everything, the names go together, Christmas cards and stuff, the 'we', 'we are going away for Christmas' it's all that, so you stay together.'

Tom recognises the times which are difficult for him - Christmas for example, and will plan for them. I interviewed him shortly before Christmas and he had decided that he would work on Christmas Day. He is clear that he doesn't want another relationship just for the sake of it and if he doesn't meet the right person his friendships are very valuable to him.

### *The relationship with Tony*

One of the ways in which Tom and Tony became incompatible was over sex. Sex is important to Tom and Tony actively encouraged him to have sex with other men because he didn't want to have sex himself. Then, however, Tony started to have a relationship with another man whilst denying this to Tom.

In the end, Tom steamed open a card from Tony to this man, he found out where he worked and confronted him and Tony. In the end he said to Tony that he wanted to sell the flat and split the profit between them,

'The following day I was straight off to the estate agents, let's get it valued, let's get it done. It was me that instigated the end, which I should have done a long time ago. I wonder why people cling on but they do, but it angered me so much...

...I find it very difficult that you can live with somebody for 18 years and I was very much in love with him. You can almost look at someone and have tears in your eyes because of the passion, it's that strong. How can you live with someone for 18 years and now I feel nothing. I don't hate him I don't love him, I feel nothing. I find that strange'

### *Housing*

When Tom split up with Tony, he got a private rented flat but he wanted the security of a council tenancy. He was not able to be housed unless he was homeless so he asked the landlord to make him homeless in order for him to be rehoused. He found the housing department extremely unsympathetic and unhelpful and the whole experience drastically affected his self confidence. He was registered homeless and the housing department wanted to place him in a hostel but he pointed out that he is Hepatitis B positive so he was placed in self-contained accommodation which was in an appalling state and took 11 days to make habitable.

'Nobody bothers...Normally I can argue for myself...but I was in shock at what was happening.' He was four months in temporary accommodation until he was rehoused.

'What still scares me is the possibility of losing the flat...nobody really wants to bother or to get involved'

Tom likes the area in which he lives, he feels it is typical of most of London in that it's rough and dirty but it is well connected in terms of travel and he has not had any problems with neighbours etc. He feels secure three floors up:

'Living in London you learn to go from A to B...if you start looking around that's when you have problems'

### *Friendships*

'I've found out with friends, it's people that take the time, when you're a bit down they say I'll come round and have a chat, it's not people giving you money, it's important to give your time.'

Tom describes the time when he was made homeless as one of the most desperate for him and a point when he really needed his friends.

'Being put in temporary accommodation, mentally, it's the only time I've ever seriously considered suicide.'

One friend helped him move his furniture, let Tom stay at his house, he showed an enormous amount of care and understanding and he gave him lots of opportunity to talk. This was the help Tom needed at what was a very desperate time.

'The friends who I have are just people I've met who've become friends, rather than have sex with somebody and then become friends, the sex wasn't all that good so we become friends. The real friends that I have, we're just friends, none of them I've had sex with. You're not thinking there's anything else there when they ring up, you're not thinking does he want a repeat of the one night stand we once had 2 years ago, there's nothing there. I've realised that friendships are better based on a non-sexual basis. It

makes things clearer. They are really coming round because they like me as a person, not for any other reason.'

### *The 'gay community'*

Tom sees the 'gay community' as the Compton Street cafe people, dressed in black and whatever is fashionable and he doesn't want to be in that group. To him the gay community also involves drug taking which he doesn't do.

Tom attends an HIV positive men's group which he has found enormously helpful, particularly a few years ago. Now he doesn't get so much out of it and questions whether he really needs it any more.

He feels that the commercial gay community is a bit of a rip off - gay shops sell products which you can buy elsewhere much cheaper - they seem less necessary now that mainstream shops have gay and lesbian sections and sell gay and lesbian products. Tom says it is similar with gay hotels - you get an inferior product at an inflated price.

'I'm not very pro gay community whatever that might mean'

### *'A typical day'*

Tom normally gets up at 8.00, runs his bath, 'make a pot of coffee and have 5 cigarettes!' He tends to go out for breakfast to a cheap cafe where he can have a fry up and this gives him a chance to talk to people and read the paper. If he is working he prepares for that, otherwise, he makes sure he has something in his diary booked for every day. On a Monday he does his massage, Tuesday he does a computer course and on a Wednesday he meets a friend for lunch. He goes line dancing, he meets his brother and very seldom has blank days.

In spite of this, Tom says there are times when he is lonely. Most of his friends have partners. He is not actively looking for a partner but there are times when he feels lonely. He tries to remember the fact that he has lots of good things - his health, a good place to live and no real money problems.

### *Future*

'I see my future as very positive...I can only see things getting better...there are a lot of possibilities'

## Participant 19 - Peter

One of the first impressions I had of Peter was his home which is full of the clocks he has collected. He finds the sound of the ticking very soothing and winds a different one to chime each week.

Peter is a 46 year old man who born in London. He moved to Stevenage when he was eight but returned to London aged 19 when he accepted that he was gay. Apart from 18 months in Buckinghamshire, he has lived in London ever since.

He was diagnosed HIV positive 1985 but he didn't actually collect the result until the end of 1986. Peter says immediately that the 18 months of not knowing was hell.

### *Growing up*

Through his teenage years Peter wrapped himself up in the church and felt most at home there as he had a very difficult relationship with his stepfather. At this point he wasn't interested in sex at all; he had his first sexual experiences at scout camp with other boys but it didn't lead to identifying as gay. When Peter first left home to do community service as a volunteer, he was accused of being gay by some of the people there.

So Peter went to London, quite purposely 'to find out about gays, sex and stuff'. He went to Piccadilly Circus where a lad came up and said, 'Ain't much rent doing around here tonight is there' but Peter had no idea at all what he meant. He took Peter to a gay bar - his first gay venue. At first he was shocked at seeing men 'dancing, kissing and stuff' - his religious upbringing had taught him this was wrong. But as he sat and watched he thought 'Why is it wrong? People are happy enjoying the company, being together...I think it was at that club at that time on that night that I decided that yes, what other people had accused me of being I actually was - gay - I think I had a nervous excitement about it'.

A few months later, back living with his parents, Peter met a man who told him about a pub that was gay in a nearby town. 'I jumped on my motorbike and went straight up there!...I didn't know what was what but wanted somehow to be accepted...I asked for a sweet sherry, well what else do gay men drink?!'

There were a few people in the bar talking a language that Peter didn't know - gay polari. The bell went, the straight people left and someone bought Peter another sweet sherry...

'My motorbike stayed up there for a week while I was brought back home in a car because they'd got me drunk...and brought me back to pick up my bike the next night...I was one of the key attractions.'

Later at work when Peter's boss told him that pub was full of 'queers', Peter retorted 'Call us what you like'.

In the end Peter told his parents he was gay because going to the gay pub became a regular Sunday evening event, replacing church. His mother's response was 'I don't know how you can say that...you've been mixing with the wrong sort of people' and carried on getting tea. His mother told his father who was extremely angry and said 'I tell you this, *if you ever touch your brother I'll murder you*'. Peter was then 19 and his brother was 10.

### *London*

Peter got to know about London through Spartacus and used to go down to the gay pubs at the weekend.

'In a very short space of time I found I was having a lot of sex with a lot of different people and I got fed up with the whole thing all in the space of about 3 months from when I decided I was gay.'

Then, fed up with one night stands, he met Tom, three years older than him 'And we fell in love - we thought we did'. Soon Tom had persuaded Peter, rather against his better judgement, to move in with him: 'It was disastrous'.

Peter had been there only a few days when Tom made it clear that, apart from sex, he didn't actually want to sleep with him,

'And we'd had quite a bit together so therefore it was a bit boring and he brought back different people he'd met so he was having sex on one side of the room while I was on my own and I felt devastated, because I felt from my Christian belief stuff that we were like married'.

Peter also started having other sexual partners but when Tom went away on holiday on his own, Peter was so distraught and unhappy he cut his own face with a razor blade. Peter eventually moved out and flat shared temporarily with an older man who mothered him, then moved again to live with another gay man in a flat share. This was close to the Heath, and although he held up a monogamous relationship as an ideal, he was having a lot of sexual partners.

Nearly 21, Peter one evening rang a helpline - he was sick of pubs, clubs and one night stands. They suggested he became a volunteer and he took to it 'like a duck to water'.

The night in the gay bar when he had first questioned and accepted his sexuality was an epiphany for him: 'a clear identification that yes I am and no it's not wrong, this is what society says. I accepted being gay as a positive honest affirmation of who you are, you have found yourself'. In this context, working for the helpline gave him 'what I needed as a person involved in the fight against prejudice, discrimination and everything else, and in all that questioning all other values were questioned' including his religious beliefs.

The congregation at the church back home were praying for him because they believed God could change him. In rejecting them, Peter rejected God. On the other hand, Peter still had moral scruples about the fact that he was sometimes 'having sex with more men than there were days in the week.'



## *Love*

At the time Peter met Kenneth he was living in a bedsit and working on the Underground.

'I couldn't touch him, I wanted to, wanted to hug him, hold him, kiss him, have wild exciting sex with him, I was just too nervous...It was like treading on untrodden snow.'

Peter took him to a campaigning group for homosexuality which met in West London: 'Mega people all being very ordinary - it was a good place to be'.

After the meeting they went home. 'We just loved being together and had a good time' The next day at 5am 'he walked with me to [work], waited for me and travelled on my train. And that was love'.

Although Kenneth and Peter were very much in love, they struggled with the relationship and the fact that they both continued to have sex with other people. Then, quite suddenly, Peter became quite ill and was hospitalised. When he was finally discharged, he decided he wanted a council flat and to live on his own so he moved to Buckinghamshire. Kenneth got a flat nearby but they began at this point to drift apart.

After eighteen months, however, Peter was very bored with life in Buckinghamshire and the 'bitchy scene that you get in rural areas. He decided to leave Kenneth in Buckinghamshire and move back to London to develop his singing: 'About the only one thing in life I've ever really had much confidence in.'

Peter met another man but that relationship didn't really work out and after suffering some homophobia at work he went on the dole.

At this point Peter was living in a south London suburb 'which to all intents and purposes you may as well regard as rural...You go in [the gay bar] any night there would be the little cliques, the bitchiness that you get in rural areas...All this who's going off with whom; they've got no bloody lives and that's all they can talk about. It's pathetic. In the centre of London you can get off with as many people as you want to in one day and nobody's going to bat an eyelid'.

Peter got a job for the Underground and was once again rehoused.

## *HIV*

One day a friend told him to watch a Panorama documentary about herpes which also mentioned a new disease which was affecting gay men in the US:

'I just knew that whatever it was I was a candidate for it'.

Over the years Peter had been treated almost continuously for various STDs. 'The only difference between me and a lot of people is that I went to the clinic and so it showed up for me that many more times'. In the gay bars the attitude was dismissive but Peter went to a meeting to talk about this new illness. Peter decided to become a volunteer in one of the new HIV organisations.

### *Testing*

Very quickly Peter was working as a volunteer for 40 hours a week on top of his job with the Underground. At the time people assumed he was positive but although he was tested in 1985, he didn't collect his results.

'I said I will practice what we know of safer sex which is not getting fucked without a condom, I was doing as much as I could whether I knew or not'.

However, Peter describes the next 18 months as hell. There was more and more publicity in the mainstream press with all the attendant homophobia and there was speculation within the gay scene about who was the most promiscuous and most at risk of contracting the virus. In the end, Peter 'phoned the doctor and said he wanted to know his results. The doctor's response was that he should wait for three weeks, and in that three weeks if every day he decided he still wanted to know the results, he would tell him. At the end of the three weeks, when Peter was told he was positive.

'In a funny sort of way I felt elated. I felt now I can begin to live with the knowledge of what I am, what I have and not the fear of what I may have, That is so empowering...I had a bloody good old cry about it and then I decided to redouble my efforts [as a volunteer] and not put up with any nonsense on the Underground'

'I used to catch my face in shop windows and see the tragedy in my face, and thought no wonder I get funny looks in the street'. He told the Manager at work he was positive and word got around about his status. Peter was given a very menial job as a filing clerk so after two weeks he left, got signed off sick and began to work full-time as a volunteer.

'I was doing things I never imagined I would be able to do, I realised I had more ability than had ever been realised by me or by anybody else; a lot of us learning on our feet.'

### *Grief*

Peter has witnessed the deaths of a huge number of friends, acquaintances and work colleagues. He believes that many of these people died in the early days because they were told that HIV=AIDS=Death, 'and they obliged, turned over and died when they didn't need to.'

### *Homophobia*

Peter talks vehemently about the 'gutter press in this country and the homophobic bigots...who are not only damaging gay men, but also killing heterosexual people at the same time, lying to readers in the gutter filth which gave licence to heterosexual people to not bother for such a long time.' He was working on a helpline when Eastenders ran the story of Mark's HIV status and numbers of heterosexual callers went 'through the roof'.

Perhaps because of the bigotry which he experienced, Peter says that from the beginning he decided to view HIV as a challenge rather than as a threat. 'With HIV, when it's something actually surging round your veins, you can't avoid that fight.'

### *Bereavement*

As Peter experienced more and more bereavement, he became almost immune to the sadness of death; 'I didn't allow myself time to grieve'. He went to some funerals but in the end he decided he could better honour the dead by getting on with his voluntary work and carrying on living. 'You can't cope with such multiple deaths, 3 or 4 a week.'. Peter describes his frustration about how, in the face of these massive losses, many of the discussions and arguments within HIV organisations were about seemingly trivial things and people lost sight of the primary focus.

### *Relationships*

Peter's current partner is also positive but in other ways they are very different and he describes their relationship as being on a knife's edge at the time of the interview. When Peter started combination therapy, his partner went away for two weeks because he said he wanted to remember Peter as he was when he was well, 'but I'm not ill and I'm not dying'; Peter finds his lack of support extremely difficult to manage.

'I wanted to prove to myself that I could love someone unconditionally...I want to love selflessly. I want to have those Christian ideals back without being a bloody martyr, without being walked over, and I have fallen over backwards...he hurts me and then I bite back...There are a lot of contradictions in me because I mean what I say and I say what I mean, I try very hard to stand by all that, but other people say I don't really love myself. He says I'm the most negative person he knows.'

### *Gay identity*

'I don't really fit the gay world. I'm a man who enjoys having sex with men, I've accepted the label gay but really if we have to have labels it would be better if I'm a homosexual. What is a gay person?'

Peter says that up until about four years ago he continued to go out on the scene but since meeting his current partner he tends only to go to one pub at the weekend and other than that they spend time at home together.

### *Health*

When Peter was first diagnosed 'I felt exactly the same as the day before I was told, physically', but there was a sense of a relief and an opportunity 'to live with knowledge rather than fear and to build on the known rather than the unknown'

A few years ago Peter had pneumonia (not pcp) and the doctors debated whether it was related to his HIV. Peter had felt proud that he had lived with HIV and hadn't developed AIDS and felt rather shocked that they were trying to give him an AIDS diagnosis.

### *Philosophy of life*

Peter conceives death as a bridge between known and unknown. He doesn't adhere to any particular religion because he feels it is 'sheer arrogance to describe God - a circle if you like, it is whatever.'

In some ways he has surprised himself because he wouldn't generally describe himself as a particularly positive person, 'but as far as HIV is concerned I have really

given it my best shot all the way along the line' He feels that spending time with like-minded people has helped, as well as the fact that, physically, he is perfectly healthy. He also feels that is significant that he is not ashamed about being gay, although he doesn't feel he 'flaunts' his sexuality, he is not ashamed, so his initial fights, working with on the helpline, was a good foundation 'for standing up for things that you know to be right and decent and proper'

### *HIV Services*

He has seen the world of HIV change dramatically over the years. In the early years treatment decisions were easier in many ways because there were fewer options, and he is concerned by the fact that many people think that the new therapies will save them.

He also has been a volunteer and involved with London HIV services for 16 years. He feels that there have been difficult times but he has avoided becoming too embroiled with the politics within the organisation. He has worked on a helpline, 'and whatever is going on around, I know that my reason for being there is for the caller at the end of the line'. He has also attended a gay men's group.

There have been so many changes in HIV services that Peter has come to realise that change is the only constant. He feels also that people are very keen to come along, reinvent the wheel and then leave again in three months time. He also feels cynical about the fact that people have made a great deal of money from HIV.

Peter changed his doctor and clinic twelve years ago because he felt pressurised to start AZT. He did not feel that the doctor's knowledge of the virus was as extensive as his own and so he felt that he could not respect their opinion.

### *Housing*

Peter now lives in a council flat where he has lived for the past twelve years. He can't really bear the idea of any more upheaval and he feels that things could be a lot worse elsewhere.

### *Changes in life*

Peter feels that being positive has enabled him to develop himself in all sorts of ways. It has led him to question what he wants to do and also what he is not prepared to do any more, 'At the beginning there was a sense of time running out and it could be running out bloody fast'. He feels it is a shame that it takes a virus for people to question what they are doing with their lives.. He feels that you should do what you want to do know to the best of your ability and build on that.

### *Singing*

Peter says that singing is very important to him but it is not something that he does, which is a great sadness for him.

'It's the one gift I've always had, the ability to sing and to sing well'

He took a tape of him singing to work once and the person who heard it couldn't believe it was him, 'because it's everything you're not - it's confident, it's alive, it's

alert'. 'It's the way by which I can best express my feelings, my emotions...I don't want to sing because I want to be rich and famous, I want to sing because I love singing, and I don't want to be involved in that rat race...my dying regret...will be that I have done nothing with my singing'

Peter used to sing outside the pub while his grandfather was in it when he was four and he joined a church choir before he could sing because he had memorised the hymns. A couple of years ago he used to sing in the church hall at the end of the road but the pianist moved away and hasn't been replaced, and he doesn't sing at home because the walls are too thin.

'I think sometimes you have to be prepared to be vulnerable, if what you want to get across is important then you have to be vulnerable'

He says that he makes excuses about not singing, 'perhaps through fear that I might not be as good as I was, and also fear of rejection'

### *Family*

Peter told his mother his status very soon after he was diagnosed. He told her on a train 'I did want her to tell her and I didn't want to tell her, and I think I was a bit of a coward'. She told his stepfather who on one visit said 'I'm sorry to hear about what you have got' which Peter feels is the best he can hope for.

### *A typical day*

Peter has been on combination therapy for a few weeks. He now is woken by the alarm at 9.00 whereas before he started therapy he always allowed himself to wake up naturally. He takes his tablets at 10.00 with breakfast, he eats and drinks as he wishes during the day, has a meal at 9.00pm and then a snack with his evening dose of tablets and then doesn't eat before his final tablet which he tackles before going to bed. Although this regime is easier than they used to be, he still finds adherence difficult, especially as he doesn't feel comfortable even within the two hour window. 'I think it's very important to keep hold of the one thing that you *do* have power over, which is taking your tablet as and when advised.'

### *The future*

Peter has never really planned for the future, even as a child. He feels there are enough things to worry about today without worrying about tomorrow.

## **Participant 20 - Graham**

Graham is a 47 year old man who was born in Lancashire and lives in London. He grew up in Lancashire, spent some time in London, lived in the Lake District and then returned to London where he has lived for the last 26 years. He used to work in the catering industry but has not worked for several years. He lives in a house in South West London with his partner, Chris, who is negative.

### *Growing up*

Graham had girlfriends at school and it wasn't until he was about 17 that he realised that he was gay. He decided to come down to London, partly for work and partly for freedom away from home. He had been in London for three months and his company had financial problems so he went back to work in the Lake District and met some other gay men. At the weekends he would go back to his parents and go out drinking with friends from home. At a party he was introduced to his current partner, Chris. He went to Manchester and wasn't happy there at all, so they came down to London. They both had been living with their parents and both wanted to get away.

Graham didn't ever tell his family he was gay, they just 'sussed it out'. He did tell his mother he was positive which he found very tough. He didn't tell them at first as he didn't see any point but when he was having his radiotherapy he looked so ill he felt he had to say something. Although she's still concerned she can also see how much his health has improved. He has a good relationship with her and his two younger brothers (his father has died).

### *Diagnosis*

He was diagnosed on St Patrick's Day 1987 when he went into hospital for an operation on some polyps in his nose. They cancelled the operation because he had 'problems with his blood' and he agreed to have an HIV test. The result was positive. He had had a lot of positive friends and, although he had practised safer sex in the '80's, he hadn't in the '70's in the days before HIV, so he believes that he contracted the virus well before his diagnosis. All the friends he had when he was diagnosed have all died; he himself wonders why he has survived when other people haven't. He didn't take any medication for about two years, then he was on monotherapy, then on a trial which he appreciated as you are so closely monitored.

Graham hadn't really thought he might be positive. He had known other people with HIV but because he had been careful he had thought he probably hadn't contracted the virus.

### *Redundancy and illness*

In 1994 he was made redundant from his job as a pastry chef at a private club in St James' 'and this was the best thing which could have happened - I thought'. They shut the place down and got rid of all the staff in a very unpleasant way, but in the lead-up to getting made redundant Graham's energy levels were very low and he was relieved that, under the circumstances, no-one found out about his status. Before he was diagnosed, his boss went to the general manager and said that Graham must have AIDS because he was gay and clearly couldn't be trusted. In the end, however, he was

sacked. Graham thinks it's quite ironic because he probably was positive but he hadn't had the test.

He planned after he was made redundant to go to Australia but at the same time his health began to deteriorate; he got pcp and KS lesions in his mouth. In the end the doctor allowed him to go 'and it was the best thing I could have done; I had a great time' but he was convinced that this was the last holiday he would ever take.

Graham now had an AIDS diagnosis which meant that it was a lot easier for him to claim benefit when he returned from Australia. He had radiotherapy on his KS for about a year, which by this time had moved from his mouth down his throat. He lost a lot of weight, his CD4 count was about 10 and, in hindsight, he would have lost his job even if he hadn't been made redundant. He believed he was dying; 'I looked a mess, and I never thought I would get back.'. Graham points out that it would be common to see people with visible KS in the early days but it is now something one sees very rarely.

Graham slowly recovered and at the same time protease inhibitors became available so he went on a triple combination and gradually his blood results improved.

#### *Health now and employment*

Graham has been out of work now for 6 years. He says he often feels very tired and he doesn't sleep well at night but he looks and feels a lot better than he has for a long time. He goes to the YMCA gym for positive people three times a week 'which is absolutely brilliant...I used to look a mess and now I look an awful lot better'. He still has facial wasting but it isn't at all obvious to people who don't know and apart from that there is nothing which makes him look visibly ill.

Graham is very very scared of giving up his benefits and going back to work. If you go to a new job and take time off sick, he feels that it leads to mistrust. He also believes that he wouldn't be employed as a pastry chef if anyone knew his status; it would be bad publicity. When he used to go for check-ups from work, he used to say that he was going to the asthma clinic and he feels now that if he did get another job it couldn't be in catering. He also wonders how employable he is now, given that he would be going back to a different job, he is 47, and he hasn't worked for 6 years - 'you have to be realistic'. He has done voluntary work in the HIV field in the past and may well do again, but again there are implications to putting this experience on a CV.

Graham would in some ways like to go back to work - he would like a better standard of living than Benefits allow; he feels some social pressure to go back to work and he also prefers to keep himself occupied. When he was in work he used to travel a lot and that's something he regrets not being able to afford nowadays but the fact that his partner has a good job makes it a lot easier to manage financially than someone living on their own. Graham and his partner, who is negative, have been together for 26 years and in some ways since he gave up work he has become responsible for the housework 'which is not what I want at all...but obviously I will do...domestic things which is only fair'

'I think it's really scary to try and get a job, get rid of all the benefits and then find out that you can't do the job, that you don't have the energy levels that you used to have.'

#### *Medication and services*

Graham has been on his current combination for about a year. He experiences some side effects, for example peripheral neuropathy, but he is more than willing to gamble on the current and possible future side effects for the benefits to his health in the present. He is very happy with the hospital he attends. He has been going every month but his clinic visits have just been reduced to every three months. He can go to the clinic, which is an easy journey, whenever he wants to, and he would almost always go to the clinic rather than the GP simply because the GP cannot be expected to be an HIV specialist. He trusts the staff in the clinic and it provides him with continuity.

He realises that, although his health is currently good, the future is uncertain and he feels he has always to have contingency plans, particularly as in about two years time he might well have to be looking at a different treatment regime and this is reliant on new treatments coming out.

When Graham went on benefits he saw someone in the CAB who specialised in HIV which he found extremely helpful. He found it very difficult to accept that he was eligible for DLA under the Special Rules and at first he wouldn't fill out the form, but in the end he needed the money.

Graham got involved with an HIV voluntary organisation both locally and in central London. He has used acupuncture for liver problems which are associated with his HIV drugs and after the treatment his tests were greatly improved. He also has found massage and shiatsu very helpful. He has worked as a volunteer in the complementary therapy department of an AIDS service organisation and also on a recently diagnosed course. This organisation has since closed which he found very shocking and very sad. When he became a volunteer, he was clear that, as well as benefiting others, it helped him to get out of the house and have something to do which involved meeting people and doing something which was valuable. Graham has also been doing a computer class organised through an AIDS Service organisation which he has found very beneficial.

Graham has seen organisations' and individuals' responses change drastically in the face of the changes in HIV. When Graham was working, no-one knew at work he was positive, so it only affected his private life. Now he socialises and spends time with other positive people and he finds it very helpful to be with people who are in similar situations. He has attended a gay men's group which has undergone a number of changes and it feels very important that people can just be accepted at face value and they don't have to explain themselves. It is also very beneficial that people at the group have been through similar experiences and can support each other.

#### *Attitude to the virus*

Graham can remember before he was diagnosed that he believed that he should avoid anyone from America. Then he saw people dying in this country and some people went very quickly. But all the time, he had hope that new drugs would come onto the market that would make the difference.



His lifestyle radically changed with being out of work - 'I was used to working, I enjoyed work' and to focus on himself entailed radical changes. He tries to turn it around and look at all the beneficial aspects to not having to work. His mental attitude has been very much linked to his physical health but he always feels a background anxiety about his health in the future.

### *Relationship*

Graham says his partner, Chris, is very scared of being left on his own. He says they don't have much sex any more and Graham feels that one of the reasons for this is because they are serodiscordant. On the other hand, their relationship has worked very well indeed for both of them. Chris takes an interest in Graham's health and is involved in that aspect of his life.

Graham's and Chris' families have both accepted their relationship and have accepted them as part of each family.

### *Socialising and living in London*

Graham tends to socialise with other positive people through the gym and a gay men's group which he guesses 'is not exactly the real world' but is something which he finds extremely helpful. He says that it is very sad that there are people who expect to have everything done for them whereas he fills his life with things that are constructive.

He feels that, although London is expensive, you can do things which are very cheap. For example, you can get a card which is called the National Art Collector's Fund which gives you free admission into many of London's Art Galleries. He is also able to get reduced tickets to the opera through the disabled access scheme. 'Although I'm not working I can still do things I really enjoy doing'. He feels that living in London has given him a lot of opportunities.

Chris is keen to move out of London when he retire in three years which makes Graham very apprehensive. He is wondering, if they sell their current house, if they might be able to afford a cheaper place out of London *and* a 'pied à terre' in London which would enable Graham still to go to the opera etc. and also to access his current hospital and the Men's Group. Graham thinks that living outside London would entail changes in lifestyle which he would be reluctant to do. He wouldn't like to be regarded as the only gay couple, in an area where they would stand out. He also thinks that he wouldn't be able to be as open about his status outside London. On the other hand, London is expensive and polluted and they could afford something more spacious for a lot less money.

### *The gay community and scene*

Graham and Chris don't really go out on the scene much at all, 'but if I did it would be there'. After his computer class a group of them go out, get the gay press and sit in either a gay or gay friendly cafe in Soho. He would far rather go to a gay bar if and when he goes out for a drink. Chris works different shifts and goes to bed early and they don't go out that often. Chris points out that there is seven years difference, he is now 54. They used to go to gay pubs but they go out less now, although Graham goes out more than Chris with his friends from the HIV field.

### *Benefits*

Graham realises that he applied for benefit at exactly the right time, whereas now it is much more difficult, but he feels it is inevitable that a lot of the benefits were going to stop given that people are living so much more healthily. Graham also benefits from the fact that he and Chris pool their money and he has a free Underground pass through Chris' work. He does feel an underlying anxiety that at some point his benefits will be taken away.

### *Housing*

Graham and Chris have lived in their current house for 18 years. It is well connected for transport and there is good shopping. They have always got on with their neighbours and there has been minimal gossip about them.

### *The future*

They have decided *not* to make any decisions about moving until Chris retires. They feel somewhere like Dorset isn't too far from London and, if possible, being able to afford two properties would be ideal if it was practical.

### *Spiritual Beliefs*

Graham doesn't see himself as a particularly religious person, he believes that when we die we probably just stop. He has thought a lot about his death but he hasn't planned things specifically.

### *A Typical Day*

This will depend on what Chris is doing. Graham goes to the gym three days a week, he goes to a Men's Group one night a week, he will often go to the opera - about 14 performances a year. He does the shopping, the gardening, his computer class and general household tasks, so his week is reasonably structured. He used to do one day a week volunteering which he is having a break from now because Chris has recently had a hip replacement. He also does social things with friends - visiting museums, going for a coffee etc. He much prefers to be out and doing something than being in the house on his own.

## Participant 21 - Paul

Paul was born and grew up in Croydon. In his late 20s he made a 'dangerously intrepid' move to South Norwood for 2 years and lived in the house his grandparents had left. Paul is humorously embarrassed about his Croydon background and says that the fact that he and his boyfriend, Rob, then moved to Hackney somewhat redeems him. In December 1985, he and Rob decided to move to Brighton and Paul has lived in Brighton ever since. He is still undecided about the possibility of moving back to London which he hasn't ruled out at some point in the future. Paul was diagnosed in Brighton in 1988.

### *Growing up*

Paul grew up 'under an air of gloom and embarrassment' in the late 1960s. By his early teens he recognised 'as far as sexual attraction goes I was attracted to people of my own sex but I was trying to fumble around for a word - there were no easy words in the vocabulary'. His parents expressed a general attitude 'which found anything with sex in the title something which just didn't get talked about at best and at worst...if something vaguely sexy came up on tele, then that would be greeted with a *particular kind of silence*.' His parents were not communicative but 'expressed by silence very often, horrible embarrassing guilt laden silence' that this was something to disapprove of.

Paul remembers one conversation when he was 14, sitting round the table for Sunday lunch. His parents might have twigged that perhaps he might be 'that way' and they had a conversation between themselves about 'perverts' 'equating that with lipstick, nail polish, handbags, all the rest of it, everything that's despicable, but nothing was said direct to me.'

'It's incredibly laden. I don't know how I managed to get through it, but I presume there's some streak of stubbornness in me somewhere, I remember just trying to find out some sort of descriptive word for people like myself. Something going on beneath this gloomy forbidding silence, but quite what that little spark was I don't know... I do remember fishing around in encyclopaedias, because there weren't any magazines... I felt very much alone, I guess.'

Towards the end of his teens, Paul began to develop a sense of self determination. He worked on a kibbutz in Israel for 6 months which was 'hardly a recipe for gay liberation' but gave him time and a fresh environment which was the total opposite of home, providing him with opportunities to meet a diverse range of people. 'I look back and see the suburban naïvity dripping off me really, a kind of awakening and a politicisation... it was an escape from the attitudes at home and a certain curiosity, actually wanting to see the world around me.' In terms of sexuality, however, attitudes there were probably worse than in Britain.

On his return, Paul went back to living at home, although he travelled on and off for about 2 years - 'opportunities for self discovery.' By 1980 he stopped travelling, returned to a former clerical job for the British Library in the Department of Printed Books in the British Museum and got heavily involved in the trade union. This led to a wider politicisation, which embraced issues of sexuality and identity.

Paul sees himself as one of the second generation of gay activists, still fired up with all the enthusiasm of the original Gay Liberation Front but bringing things into the workplace. When he was elected onto the Trade Union Committee, he was always an out gay man and he was voted in at successive elections for 8 or 9 years. At the time there were a few people out in politics, but there was a precedent in the legacy of the GLF plus writing by people such as Jeffrey Weeks.

Paul describes this time as 'immensely exciting and energising, right across the board.' Mrs Thatcher manage to galvanise, 'I was going to say the loonier fringes of the left, but the ones where I used to hang about anyway...It was the old days of personal is political - of course things intertwined.'

### *Coming Out*

In terms of Coming Out to his family, 'I'm afraid I used their tactic which was meaningful shades of silence. Obviously nothing was denied, but I think I did use silence to come out...communicate in their language, which I'm still not happy about in retrospect, I think I could have done better.'

Paul describes an incident at his sister's wedding reception. 'There was myself and the usual bevvvy of old aunties and my mum handing round a plate of sandwiches, and one of these old biddies said, and when's the happy day for you Paul? I quickly did a think - coming out is the right thing to do but potentially could spoil a unique day for my sister. Before I could make a decision my mum had spun round and said 'Oh he's not met the right girl yet.' Recognition but denial.'. Paul's mother died 3 years ago. His father's still alive, but 'his social competence is very low. In that context it's not surprising that he hasn't said a word to me for about 20 years, but it's not even to say 'hello'. It's part of a long standing pattern...He's probably written me off actually. I don't know because we don't speak.' Paul keeps his sister informed about his health but, because she is very conservative in her attitudes, he doesn't discuss anything to do with his sexuality with her. 'It does get responded to and therefore acknowledged, but it's not really got to grips with. It's a bit like my mum's attitude - acknowledge and deny.'

The affect of his family on him? - 'It fucked me up! Drove me to drink it did!' He quite consciously decided that in social situations, if he did the opposite of what his father would do he'd probably be doing the right thing but he still struggles with shyness and has to force himself to be outgoing and to take social risks.

### *AIDS*

At the time of the interview Paul was re-reading Daniel Defoe's Journal of the Plague Year, and was struck by the parallels with the early years of AIDS - the rumours of plague visiting Amsterdam and the papers embellishing the story for effect. The first mention Paul heard of AIDS was from a colleague at work and the first time it directly affected him was in the late 1980s when a colleague died of an AIDS-related illness.

'It seemed to creep up very quietly. I seem to remember being more concerned about basic issues of lesbian and gay equality. I think I'm as guilty as anybody for not

responding to something until it had hit me. I think it's a human failing, it's often the case, but I don't think there's much excuse for it.'

Paul remembers the prurient headlines 'revelling in sex and incurability' and the gut homophobia - the car stickers which said 'Help stop AIDS - run over a queer today'

Paul and Rob both thought they might well be positive but at that point they saw little sense in getting tested - at the time HIV was incurable and terminal, 'and that is an awful lot to choose to become aware about in one's own self. Denial might be the word, but there is a kind of protective mechanism, there is only so much one can deal with. As it stood then you could move forward with only immense difficulty in terms of your own health, in terms of your standing in society, with neighbours, work colleagues, family and so on.'

By the late 1980's, Paul was working a twelve hour day, including the commute from Brighton and was beginning to feel quite run down. His GP suggested he had an HIV test 'which I didn't protest about but I remember being unhappy about'. He knew the result would be positive. He was almost 'beyond feeling'. He was given the result by a counsellor 'who told me with tears in her eyes, which struck me as her expressing her problems in quite the wrong environment. I think it's absolutely gross, grossly unprofessional. There was a confusion on my part at that environment that she'd set up. Potentially disempowerment of myself, but actually straight into a kind of blankness.' I can't remember what went on after that. I do remember walking home along the sea front. It was quite a nice September day and people were out there, people down from London enjoying themselves and me in quite a different frame of mind, and I got home in a state of shock and confusion.'

Rob didn't get tested for another year although they both assumed he was positive as well. Paul has blanked out the follow-up sessions he and Rob had with the counsellor, 'They were all about death and dying and how to adapt to mortality - for me and also to my boyfriend in relation to me...This was the atmosphere which if he'd chosen to get tested he would have come into. So any reluctance on his part I more than understand.'

Paul found it difficult that Rob didn't get tested and it almost led to their relationship splitting. He was advised not to tell people his diagnosis but he did tell Rob and he told his mum, and he told people he worked with 'who were brilliant, even if I wanted to fault them I couldn't. They were exemplary, particularly at that time. It probably gave me some real encouragement without expressly doing that.' There was also a lesbian couple next door who were 'huggy and encouraging in the right sort of way'. Paul feels that there were tensions within his and Rob's relationship which weren't explored and resolved; 'I think looking back Rob did have some sort of nervous collapse, something quite serious. Not bad enough for hospital treatment but disabling in terms of his relationships with people.'

### *HIV Services*

At the time of his diagnosis, Paul believes that Clinical services in Brighton were substandard. 'GUM was gradually faced throughout the '80s with a new serious infection. There was some rapid learning to be done. Some people rapidly learnt and others didn't. I think it is the case that the doctor in charge was a slow learner, that

was the public face he gave. There is a quote in a Brighton local rag in '84. when AIDS beginning to be recognised in Brighton as a real problem. He said there is 'Absolutely no concern, there'll be no epidemic here'. Paul had a meeting with him a couple of months after Rob died in October '93 and Paul suggested that an HIV consultant based in Brighton might be beneficial. His response was that there was no need. 'Fucking disgraceful is what I call it...He had absolutely no right to be patronising to patients. He should give a welcoming ear to people's concerns, even if those concerns are wrong, get some dialogue'. On the other hand, within the clinic there were two younger doctors who have since left who Paul feels were far more informed and responsive. Paul coped by using these two doctors and avoiding the consultant.

When asked what was difficult at this time, Paul says 'Being faced with mortality, the big issues of life and death...Almost seeing predictions of early demise confirmed inasmuch as people one knew, friends or a regular face in the pub gradually dying. That became a recognisable pattern from the late '80s and early '90s. Fitting it in with the chronology of my own diagnosis, it just seemed a hopeless situation. I suspect that if I'd been living in London I would have found it different, I would have been aware of support groups whatever. I think more likely than not I would have got in touch with one of them. I don't recall anywhere in Brighton that sent out hopeful and constructive messages, i.e. of being on the political ball as much as anything, that would have attracted me.

Paul did have things which helped him. He received some support from a man who was diagnosed just before him and his neighbours gave him a book by Louise Haye 'which I think can be pulled to pieces constructively in any number of directions but at that time of immediate diagnosis and certainly for months after, I found that approach useful. If it is used wisely, it is an attempt at self empowerment. If it's used badly you can blame yourself for anything that goes wrong with your body.'

Paul has been seeing his 'shrink' - a clinical psychologist - for ten years and has found her immensely helpful and supportive. He quickly built up a good professional relationship. Paul decides what they look at and she keeps things very much to the point. He started going to see her at the time of Rob's first AIDS related illness when Paul was dealing with Rob's health problems, Paul's own diagnosis and their own relationship difficulties.

'Even when on the face of it there's nothing going on, it pays me to go...for an hour's session about once every six months...a safety net'

### *Rob's diagnosis*

Rob by now was losing weight and was generally unwell. At the very end of 1989 he was tested positive and was swiftly admitted into hospital with what turned out to be pcp. 'He just about managed to stay the right side of the life-death divide. He was a stubborn old thing, which I think helps. We thought he was going to die.'

By this time Paul was having a relationship with someone else, which Rob knew about. 'The one saving grace about [our] relationship was its openness and honesty, even if it's something you don't want to hear about, but at least you know what the ground is.' Then Rob also began another relationship and his new partner moved in

with them 'Yeah, I know, well we thought we could do some sort of bohemian constructive life and challenge heterosexual monogamous norms blah, blah, blah. You can still challenge the heterosexual marriage norm but not in this way! It set up too many tensions all round.'

Over the next three years, however, Paul and Rob became much closer, particularly on an emotional level, which Paul thinks was at least in part a result of both being in the same emotional space in terms of their HIV. From this point, Paul was in effect Rob's carer. He noticed that this role in many ways made him invisible; people would ask about Rob, 'phoning Paul all the time expecting him to relay the news over and over again but never asking about how he was managing; 'That sort of thing doesn't even enter people's minds, which is wearing, especially when it's coming on top of one's own confusions, fears and anxieties about one's own health.'

After the pcp episode Rob regained some strength and was reasonably healthy for another two years.

### *Living in Brighton*

'I'm still trying to kick Brighton's services up the arse...Brighton is 50 miles away and a generation or two back in time.'

Although there is a large gay population in London, Paul doesn't like it and prefers to come up to London to socialise. There is a desperate desire for anonymity which means that people are unlikely to be open about their sexuality let alone their HIV status.

'There are individuals coming into mind who would never have anything to do with gay pride because...what I do in bed is nobody's business - well that's just self loathing closet! And you'll find that is a more widely held attitude in Brighton than you'd expect and it goes with HIV stuff as well.'

Paul would call it a gay 'population' rather than 'community' 'because it's so disparate, you can't put your finger on it. It's got similar small town qualities of incestuousness. Everyone knowing everyone else's business, or everyone knowing your sexual preferences...you still get that up here in London but numerically the chances are less likely that you'll bump into somebody who knows your sexual business.'

Paul hasn't discounted the possibility of moving back to London. He uses the London gay scene most weekends and some weekdays; he finds it more dynamic, more exciting - 'I can relate to it and feel its equal much more. I came out onto the London scene anyway.'

Paul also finds that he is associated on the Brighton gay scene with HIV organisations. There was one incident where a volunteer at one organisation pointed out his address to another service user who then came to ask him at home about combination therapy. Paul refers angrily to 'the first wave of volunteers, middle aged or elderly women who were doing good work, for all I know building up surrogate families for themselves.'

Brighton has not been a support in spite of the fact that there are a lot of services and Paul feels it has been getting worse. He describes himself as walking a tightrope: using the rail service as a connection between the good bits of London and the good bits of Brighton.

### *Rob's death*

In December 1992, 2-3 weeks before Christmas, Rob suddenly started to experience pain and difficulty breathing and was admitted to hospital. He was kept in Ward 6 at Hove General - the AIDS Ward by any other name. Over the next few weeks all they could work out was that he had serious chest problems which was impeding breathing, but they didn't know what it was and it took 2-3 weeks for them to diagnose the lung cancer which eventually killed him. From this point on he alternated between an in-patient bed and home and Paul became a full-time carer.

'He'd wake up with inability to breath just from the pain. We agreed it would be alright for me to go out on a particular evening, and he'd be alright for 3 hours and I would get back and find he was unable to breathe again.'

This went on until his death in July 1993.

Paul is incredulous that Rob's lung cancer was not diagnosed for so long when in fact Ward 6 at Hove General was run at the time by a chest specialist. 'I was thinking of making some kind of protest at the time but Rob didn't want that and I think he was right in terms of his own life at that stage. It meant he could concentrate on accepting the illness and I could concentrate on trying to be reassuring as far as possible, and the last few days as he was dying just getting the right environment in the room - he was particularly after calmness and dignity and that's what he got. But I'd still like to know how a chest specialist misses lung cancer.'

Paul did feel, however, that the staff at the in-patient unit were very clear with him in explaining that Rob was dying and exactly what was going to happen.

'I still had this lingering attitude about death from my parents and particularly my mother that it's this horrible horrible thing that you just don't talk about, yet another 'embarrassing life thing'. I made a conscious effort to override that by asking Rob if he wanted me to stay...with him over the next few days and he said yes, so that was the initial bit which was difficult but I overcame.'

All this helped to build up a picture that was distressing but not in the way death had been presented to him before as a child as not just terrifying but also in some way disgusting and taboo. 'No matter how horrible or frightening something is, if it's inevitable then I'd rather look at it, break it down and understand the little bits, then you can start dealing with things'.

'I remained with Rob, most of the night, came back into his room immediately prior to his actual dying and just sort of held him. He died with incredible quiet and dignity and calmness which was everything that he'd asked for and everything I'd been working towards in terms of setting an atmosphere in the room and getting the feel of it right. He died in this incredibly dignified way...I felt at that moment that we were probably as close - in spite of our relationship being at one point about to break -



coming back from that distant point back to that moment he was dying we were as close as when we were first in love 11 years before. Completing that sort of relationship circle from first love through to potential split round again to last love if you like.

### *Bereavement*

After Rob's death, Paul describes himself as 'utterly distraught, desolate, this central person in my life was physically not there any more.' He and a few friends organised the funeral, and in the following October he scattered the bulk of his ashes on the south coast east of Brighton. Some of the ashes he kept back to mix with his when he died, although subsequently he has come to question whether he wishes to do that as his life has moved on. In fact, it has only been this year that he has finally felt he has accepted that 'he's not here any more and that I'm here specifically as a single gay man in Brighton.' and he has expressed that symbolically by clearing out his books and selling his piano.

Soon after Rob's death, Paul was asked to chair the management committee of an AIDS Service Organisation in Brighton which was experiencing a lot of acrimonious internal difficulties. Paul found the work 'physically wearing and very stressful, like trying to keep your head above swilling poison'.

Paul found that there had been significant misappropriation of funds and it took a lot of energy, time and effort to keep the organisation together. 'I put grieving on hold, activism was uppermost'. In fact, Paul became involved throughout 1994 in a number of voluntary organisations.

In late 1994 he stood down from his various commitments and gave himself time to grieve. In some ways he tried to force it, to rush it, to 'see it as a rational problem with a rational solution, but it's not that neat'.

Three things came together. First of all Paul moved to a flat on the ground floor as at the time he was worried about the future. This also coincided with some homophobic bullying from some of his previous neighbours: 'spotty 13 year olds; that difficult age to deal with because you can't take them out and punch them...and it didn't help that their father's a stupid oaf with a baseball bat'.

Paul also went on holiday with some of the money that was left to him, and although he finds the phrase 'letting go' rather glib, it was healing in many ways. He started off in Islamabad in Pakistan, then drove the Karakorum highway over the top down into Western China, up to Kashgar, the old silk road trading centre, then west into what used to be Russian central Asia to Samarkand and Bokara. Paul describes it as 'stunning, a brilliant journey, my own personal trip of a lifetime...My shrink would say very predictably, it came to assume an importance in accepting Rob's death as opposed to having a list of those rational things that you do and tick off.'

At one point they stopped at a deep gorge at a point which was overlooked on one side by the Himalayas, the Hindu Kush on the other side and the Karacorum ahead. There was a memorial there and the inscription on the side is about the meeting of these three enormous mountain ranges.

‘Everyone else was doing what I would have done under other circumstances, chatter, look at the inscription, take a few piccies, walk about, but in fact I took myself off on my own for a bit of quiet, initially to add my own little pebble to the pile of pebbles, I thought I'm going to stick mine on there and, cliché or not, it's for me on my earthly journey and Rob on his other one...the only conscious element was picking up a stone with the intention of putting it on the pile, and from thereon it was a series of actions which were happening of themselves...I found myself doing that, sitting down and quietly taking in the atmosphere, the sense of the place, which fitted in with ideas (from daoism) about cyclic wholes, like that sense of being in love, beginning and ending, that circle completing, aware of opposites which shape each other, all of that...

...I was just sitting there quietly sensing all this and quietly in it. I had a feeling of what some people might describe as Rob's spirit, I think it was the essence that gave Rob his self, which I'd last noticed at the actual moment he died, and this was here. It was around for a little while, and then it seemed to go. It was almost physical but it wasn't. The Karacorums are a very jagged range and they were ahead of me and there's a skyline and blue sky. On the outline there was a sense of something infinite through there, a sense of real quietness, and that's where this essence of Rob went to, his time here was over and he was going on to that stillness.’

It felt that the one thing left was the portion of Rob's ashes that Paul had saved and he decided to scatter them. ‘It felt sad, but right. I had a feeling that I was letting go of something more’. Paul says he gets the odd twinge occasionally but now on the whole he sees himself as a single gay man who would rather like a boyfriend, ‘so I'm looking forward again with an easy heart.’

### *Relationships*

Paul says he used to be adamant that any boyfriend would have to be negative but then on the other hand positive people can provide each other with peer support and mutual understanding. Now he feels he takes a more balanced view. He thinks that the issues that come up either way ‘can be dealt with, accommodated, got round, understood, as long as you talk, as long as there's this thing called dialogue in the relationship, it's something I'm very keen on anyway, openness and honesty within relationships.’

### *Survival guilt*

Paul says that he has used the London gay scene for support around HIV health issues, which he feels is ‘yet another indictment on services in Brighton’. Throughout 1996 Paul found that the cumulative grief of multiple bereavements was sitting very uneasily with his ongoing physical relatively good health: ‘I couldn't bring these two together in a way that felt easy and right in the slightest, but didn't realise the extent’.

When once again his blood results were good his doctor's response was, ‘so it looks as though you're probably be long term, you'll be delighted to hear’ - Paul wasn't. ‘Decidedly the opposite...Something which had been developing really came to the surface, a developing sense of profound depression...swirling chaos, not being quite suicidal but that was something that was beginning to come onto the agenda’.

Paul's response was to telephone his 'shrink' - a psychologist, and he also went for help to the various local voluntary organisations. The response was extremely poor. He was asking for support, preferably peer support but was given no help at all. One organisation 'were up front enough to say they couldn't help me, but one or two of them gave me the hugs and kisses that the old busy brigade do in lieu of anything useful...I was stating a real need and should have been taken seriously.'

Paul's shrink, however, was reliably there for him at a time when he felt extremely unsupported. Last year he found himself getting depressed again. This time he was more able to manage alone but the fact that his shrink was there gave him confidence: 'it's knowing that you can dig around, not wallow in the shit, but dig around, explore it and then climb out the other side'.

Paul also derived support from one of the London nightclubs called 'Warriors', which Paul describes as 'genuinely fully welcoming for people with AIDS and...also holding a reputation for playing the fiercest music possible and from that being pretty intimidating as a club...It was a club full of the most extraordinary extremes in terms of club behaviour - desperate, a club with casualties in some ways. But in the upstairs café, there was a sheet with the words Positive Zone on it, the biggest upfront supportive thing I could possibly have wanted and it's there right in my face. Every positive message for someone in my position. There was a camaraderie and people were actually really friendly. I became a regular...I would go to this club, declare my status and be given members' privileges. Everything was turned around in a positive helpful way, empowering way. I got a hell of a lot going to that club, it's bizarre but I did...Warriors still has a particular place in my affections.'

'You did hear stories about people with AIDS not being treated well in gay clubs. I remember in Warriors one night seeing a bloke...with an incredibly beautiful face but with really serious KS all over it, but here he was someone who was having a night out in a club, he wasn't that person over there with a blotchy face. There's a major difference.'

It is important to Paul to feel that he is part of the community which makes up the gay scene and he has worked hard at being accepted as part of that community.

#### *The energy of local services*

At the time of my second interview with Paul, he arrived extremely angry because he had been to a conference about the future of HIV services. He had organised his own funding to attend this conference and had liased with local organisations about it. In the end, however, he was the only person from the Brighton area to attend and he felt that this was a real indictment of local services, demonstrating a head in the sand approach to the future of HIV services in general and their own services in particular.

He feels that the mindset of the local organisations is very stuck. 'One of the old women buddies from the way back early days - the ones who came running to befriend us - still goes along to one of the drop-ins and collects her free meals as if she's still doing something but she isn't...It's the whole atmosphere, everyone involved in that allows it to continue.'

He feels that within these services he has a reputation of being 'the tolerated angry person because there's more or less only one of me that's looking over the parapet and seeing the picture...An irritant, or a Tony Benn position of someone who's allowed to be radically different, knowing that the rest of us are so secure that we don't have to take any of what he's got to say on board.'

'I'm aiming for realism and trying to suggest ways of working with the situation. It's fair to criticise constructively and it's also fair to praise when things go right and again I try to do that.'

'On paper some of them can make a case for remaining open for another one or two years, but if I were a funder I'd actually be calling for an audit of the genuine activities of those 5 organisations...if you gave me that magic wand that solves everything I would...close all the organisations and reorganise them according to...the areas in which they do well and areas in which they do badly...I might include a few individuals who are shit hot in that field...On paper you would have a smaller service provision, but it would be targeted and aware and responsive.'

### *The Future*

Paul, at the time of his second interview was planning how to combine his desire to improve local HIV services with the sense that it would be sensible to plan to return to paid work...' I feel I may or may not at some time be called up by the Benefits people and kicked back into work...and I don't want to be kicked in at the bottom'. He has been working towards a City & Guilds Adult Teaching Certificate and has applied to do teaching practice at one of the local HIV organisations. He also applied for the post of Service User representative at the local out-patient HIV clinic. 'In clinical terms Brighton's in a good position and the clinic seems to be making head way, it's just the voluntary sector's got to catch up.'

In terms of returning to work, Paul has been planning by increasing his voluntary work to see how he manages the rigour of a working environment in terms of his energy levels. He is 'feeling around, hopefully intelligently so, trying to get a practical picture together. I can't say I'm not worried about it, I am, but I feel it's a concern that can be met.'

'It's a step that agencies could be, not pushing, encouraging, but down there I don't see sign of that...It's an indictment of a shabby attitude and a shabby service. The worst thing that can happen is a few years down the line everyone's called in by the Benefits people, and are now job seekers. How can those individuals manage to achieve anything if they've been let down by services who year after year have not addressed that issue?'

In terms of his own future, Paul feels his personal sense of future is definitely getting longer and, from not being able to look much beyond the next day, he can now imagine reaching normal retirement age. At the moment he is treatment naive but during the various summer Prides he finds that his viral load goes up.

'I do like going to all of them...and take whatever is needed to carry on till the next morning. A string of hectic weekends, but ones which do have an impact on the body, anybody's really, weekend after weekend...at the moment I'm doing what I reasonably

can to push treatments back a bit. Physically I'm in a very strong position and I'd like to keep it that way, but I don't want to lead the life of a monk or a hermit!

When I met Paul again, his viral load had halved and his CD4 count had maintained at around 500. His doctor says that no research to date shows a correlation between recreational drugs and suppression of the immune system, but Paul feels that, even if the drugs themselves don't directly affect the immune system, the activity around their use probably does. Paul is attempting to bring his clubbing down to levels which his body finds more tolerable - probably about once a fortnight, 'I'm happy with it at a ticking over kind of level, so I get my release but which doesn't do my head in which staying indoors does.'

#### *Work, continued*

When I met Paul for a third time he had started work as the service user representative at his local clinic - a new post, which as far as he knew isn't replicated elsewhere and which he has a strong hand in shaping. As far as he is concerned he is hoping that it will be a good practical step in terms of career development. In a month's time he plans to go for an away-day with other clinic staff and give a presentation about his post, which he feels demonstrates that the work is being taken seriously. He will be splitting his time between the clinic and on the ward as well as making links with other agencies and their own service user reps. He hopes that he can set up a service user rep.'s forum which will facilitate networking, communication, presenting a unified voice etc.

Paul had also followed up his training work which was also progressing. This, however, involves attending a basic HIV awareness course, the irony of which was not lost on Paul, although he conceded that observing a learning environment might be useful. He also thinks that he might at some point in the future be able to assist the clinic consultant with his presentations. In all of these new developments Paul will be able to make use of contacts he already has in London.

#### *Homophobia*

Paul recalls two instances as examples of overt homophobia. He was in a greasy spoon in Central London with Rob in the Winter of 1982, 'we were in there for something to eat, a cup of tea and a snog'. Rob went to pay and the man and woman behind the counter began to lay into him with 'gutter homophobia, Pavlovian homophobia - you couldn't tease it out and reason with it'. Paul was just about to open the door when a middle aged man in a dull brown suit who 'just reaked of a dead end office job' opened the door and he started having a go at Paul. 'I just told him to fuck off and punched him in the stomach and then we did a runner!'

About a year later, Rob and Paul were travelling home from London and were waiting on a platform at Charing Cross Station. They were sitting on a bench and Paul had his arm around Rob. They were approached by a gang of lads 'and I thought, fuck, we're in for it now, because it was bloody obvious...what we were.' As the gang walked past, one of them came up to Paul and said 'Eh, Are you gay or something?' and Paul said 'Yes'. The lad replied 'That's good that is, that's really good!'

### *Spiritual Beliefs*

Paul says he suspects he does have some but against his better judgement. He rejects the Christian beliefs he was educated into. He is very antagonistic towards Christianity because it has shaped our culture, but also Islam and to a lesser extent Judaism. He tends generally to be suspicious of established religion. On the other hand, he has read about Taoism and books by Lao-Tse and compares it favourably with Genesis. In Genesis you are given a concrete concept of God who is conceived in human terms whereas in Taoist thought you are given a sense of creation and being but nothing concretised. He likes the Taoist idea of cyclic opposites rather than conceiving life as a linear thing.

Immediately after Rob died, the nurse and Paul lowered the bed and straightened his head on the pillow. 'There was something about seeing him in that position and the closeness of that moment felt like coming back to a sort of beginning...that sense when you're first in love with someone' - the relationship had gone full circle, from the time they first met, through antagonism, back to an extraordinary closeness. It seems to make sense in terms of a cyclical way of looking at things.

### *Friendships*

Paul finds the continuity that enduring friendships provide him in terms of his own life are incredibly important. Part of the survivorship depression was the sense that people who had helped to shape him were gone. Now, although he has one or two enduring friends, he has more of a sense that people move in and out of his life and there is more of a sense of fluidity.

### *Effect of HIV on his life*

Coming into Paul's life at the time it did, with the meanings that it had at that time, 'it fucked it up. It killed my boyfriend and loads of other friends', ideally he would still be in work and HIV challenged him profoundly in terms of surviving with it, 'but something has strengthened me with it', he has become more mature, less naive, more aware of issues of mortality and more aware of his strengths and abilities. 'I'm angry and frustrated at things which are horrible but can't be changed.' On the other hand, as far as he can, he engages with HIV as an empowering thing and attempts to control things in his life as far as he is able to.

Paul also feels that his relationships with people around him are much clearer. If he feels that maintaining a relationship with someone is deleterious, he will end that friendship. He gives an example of someone he has known as a good friend for a few years. Paul found out he was positive but hadn't told him, even though he would discuss Paul's status with him. When Paul found out, his friend wanted him to keep the information strictly confidential, and although Paul would respect someone's right to keep control of personal information, as a survival strategy, it was harmful to his own way of being, so he had to let the friendship go.

Paul also gives an example of a friend who was diagnosed 18 months ago and was immediately offered support and encouragement from his friends including Paul. However the friend wouldn't discuss it at all 'to the point where he was running away from life entirely into a horrible almost text book downward spiral.' Paul realises that he is not able to help this man because his offers of support are being continually rebuffed: 'I'll reach out my hand...but you have to reach out and hold it'.

### *A typical day*

Paul doesn't have a regular daily timetable. He doesn't necessarily sleep well but he usually wakes up around 7.00. He gets up, listens to the local radio, even though he thinks it's atrocious! He will probably read the chapter of whatever book he's reading at the time, at the time of his interview he was reading *The Debacle* by Zola and Peter Ackroyde's *Biography of London*. He will then do some HIV related work. He may have lunch, or meet up with friends for coffee. On Mondays he goes to London to a gay men's group and in the evening he quietly winds down, having something to eat, smoking a joint or two and playing whatever music feels right for the day, often something classical.

### *The good things and the difficult things in Paul's life*

The Clinic and the teaching course are things which Paul finds simultaneously good and difficult. One thing in his life at the moment which is good, and, hopefully, not difficult, is that he 'copped off' with a bloke at Trade at New Year. Although he is not Paul's 'type', the bit between the sheets was nice and he's decided to stop analysing it and is just enjoying it! 'It's fun, it's really nice. I haven't had that access to intimacy...physical intimacy...I haven't had that outside the backroom at Fist for a long time. It reaffirms one as a person...reaffirming in that warm, human way.' It also, in spite of it being a bit of a cliché, felt significant that it happened at New Year: 'Even if I don't see that bloke again, something good is there now'.

When he considers taking photographs to accompany his interview, Paul reflects on his relationship with the reading room at the British Library. Rob always had said that he was married to the place, and in some ways he was, it certainly came to represent his working life in London. He went back to look at it now it is no longer used and although it is still architecturally stunning, it is now a dead museum piece.

It is the same with the Pied Bull in Islington which used to have the gay and lesbian disco for all the lefties on a Friday night on one side with the skin head Nazis in the other bar. This was where Paul met Rob in 1982. You would come out of Angel Tube which was hard and rough and then one bar in the pub was the meeting place for the gays and lesbians and the other on the same night was a meeting place for skin-head Nazis. Paul recalls hearing of a night when someone was thrown on the train line. He went back to find that it has now become an 'All Bar One'. He also recalls 'The Bell', which has also been renamed, in Kings Cross. In the '80's it was the trendy gay place to go and was a venue for 'The London Friend'. 'The Jarman's of this world used to hang out there'. He also has fond memories of Jubilee Gardens which was where Pride used to end. The gardens have also hugely changed with the passing of the GLC and now the London Eye; 'things have been rubbed out...20 years in London just doesn't stay still'

## **Participant 22 - Nicholas**

Nicholas is a 34 year old man who was born in London but brought up in North Devon and North Cornwall. He has lived in London since University. He was diagnosed between 4 and 5 years ago.

### *Growing up - rural society and the navy*

In the country there were no examples of quite what a gay person was, 'gay was something that people were in the cities, the country is strange...nothing is ever said.' Nicholas did have sexual experiences with other men from twelve onwards and he was molested by several of his teachers but he didn't equate any of these experiences with being gay until his late teens. He joined the navy and at 18 he was aware that he was lying when he answered the question, 'Are you a practising homosexual?' Without any role models or any positive gay experiences 'I had nothing to want to be'.

Nicholas remembers a famous court case when he was 9 or 10 which caused a lot of discussion around 'seedy seaside hotels, but it didn't map onto me'. There was a lot of 'liberal homophobia' around the time Mrs Thatcher came to power; the issue wasn't really ever discussed.

He 'escaped' from the country by going to university but it took him until he was about 25 to come out because of his rural background. He joined the navy for a year and then they sponsored him through university. At the end of his degree he bought himself out which cost £7,000 - if they had found out he was gay he would have been sent to Colchester jail. 'You could say I ran away from it all - but not unsurprisingly'. It wasn't the money which bothered him - it was a debt he just paid. The thing which does annoy him was that he was treated like that and he has known other people's lives destroyed by this policy:

'Until there is a formal apology I will never forgive them...'

Nicholas says that the straight men in the navy were perfectly prepared to protect their gay colleagues and there was an undercurrent of resistance running throughout the service. There are also tacit exceptions such as the Royal Yacht 'which is basically a posting for upper class rich queens...you get accepted as long as you stay on the vague, predefined side of the line...you cannot be open about your sexuality whatsoever, although you can be as camp as tits'.

Nicholas feels that, although a lot has changed, a lot still has to change, including the religious right,

'which need to be taught a thing called tolerance...At the end of the day a generation like me will stand up to them, and will give them back as good as they get and they have not been forgiven...a minor change of the law which can be reversed on a government whim is not really good enough...it's not really a question of equalisation of rights, and some wrongs being righted, and some apologies being made, it's a bit more complex than that. It's a whole shift in the attitude and we haven't got there yet



and I don't think we will for another 10, 15, 20 years...and I am very wary of a lot of politicians...and of middle England, because middle England is rural England'

Nicholas decided that the only way he could cope with the policy was not to be sexually active. On the other hand, one of the men who trained him *had* been sexually active and, when he was caught, everyone he had trained for the past four years was systematically interviewed. Significantly, no-one gave the naval authorities any information at all but the man was still sent to the military prison in Colchester.

Nicholas points out that, even in terms of the country, Cornwall is very cut off, even from Devon, and attitudes are very much stuck in time.

### *Rural Cultures*

Nicholas has done a lot of caving over the years, putting him in touch with rural cultures in the North of England and Wales. He says that many people haven't noticed that he is gay and are surprised, but there is a level of tolerance that wasn't there a decade ago. He also notices that he is no longer needing to defend himself because more of the people around him will also challenge any homophobic attitudes.

He thinks that this shift in attitude is the result of 'thousands and thousands of people standing up in their own small way'. To an extent government policy and pressure groups have made a difference but 'the reality is that for all the initiatives and good works...and the legislative framework...really [these are] dragging behind reality...but that is a city view, I am a city person nowadays. He notes in terms of regional differences how, if he wears a red ribbon in London, the North of England and North Wales, the ribbon means something very different in these different contexts.

After leaving the navy, it still took a while for Nicholas to Come Out. He was doing a lot of caving and was aware of the risk to many of his friendships if he Came Out. In fact this has never proved to be an issue but he feels rural attitudes were a major factor in persuading him to remain in the closet. Nicholas went to an engineering university, so although he was living in London, there were still a lack of positive images of gay men and he still encountered a lot of brutal prejudice, all of which discouraged him from Coming Out. In the media, it is always assumed that gay men 'will wear effeminate clothes, will be horribly camped up, will be a hairdresser and will only be interested in shopping...our society tolerates you as long as you correspond to that image'.

Nicholas has done world class caving and has been involved in a lot of cave exploration. It is a major part of his life and he pursues it to an extremely high standard. This is, in the eyes of others, an uneasy juxtaposition with his sexuality.

Nicholas points out that there is a lot of negative publicity about gay men in the press, particularly gay teachers abusing their pupils, but he feels that the society that forces people into the closet is at least as responsible as those individuals.

### *Family*

Nicholas's parents were both quite old when Nicholas was born and both of them had died by the time he was twenty five. He doesn't have a great deal of contact with the

rest of his family although they have been quite supportive about his HIV status and have made an effort to find out about the virus.

### *HIV*

Nicholas was at University at the time Freddy Mercury died and was always aware of HIV. He knew that he had had some 'unsafe sex interludes' so was aware that he might be positive. One of his former sexual partners tested positive which led him to go for a test, and at the same time his health was deteriorating. He thinks he was probably tested about a year after infection. His counts were not good at the time he was tested and within a year he was on dual combination therapy. Unusually, his Viral Load became undetectable on dual combination - AZT and DDI - and he felt a lot more healthy. He suffered from some side effects but he thinks that the fact he has a strong constitution helped him to withstand their toxic effects. As soon as his Viral Load became undetectable he stopped the drugs and for two years he hasn't taken any antiretrovirals. So, 4 or 5 years after diagnosis, his health is a great deal better, he is able to work and he is still reasonably treatment naive.

Nicholas says he had been doing a lot of clubbing, he was not looking after his health and was underweight. He has worked hard to regain his health and strength, so he feels that his own efforts have very much contributed towards the success of the antiretrovirals.

Although Nicholas was expecting a positive result, he didn't expect 'the mental rollercoaster' which he was on for several years after diagnosis. When he came off the antiretroviral drugs, 'I was critically aware that the body was on its own, so no clubbing, no wild behaviour, you look after yourself...I remain a cynic about how long the drugs can work for'.

When he has been unwell - he had an abscess and he has recently suffered from chickenpox - his Viral Load has increased enormously, but it has always returned to undetectable levels once he has recovered.

### *Services*

Nicholas has had the same doctor for 5 years and has also been involved with London HIV services so has always been reasonably well informed: 'NAM allows you to check the doctors'. He admits to feeling exposed in the middle of the Mexican jungle - miles from the nearest hospital! He has to smuggle all his drugs into the US, although no-one suspects he is gay or HIV positive because he's a potholer!

Soon after diagnosis, he went on a recently diagnosed course and stayed involved with that particular HIV organisation. He has criticisms of one organisation as having lackadaisical and inefficient management but at the same time remained deeply customer focused so he was very disappointed when it shut. He criticises a current HIV organisation as lacking that commitment to its users.

'You judge organisations by their actions'

'The days of your cottage charities are over...the way is not complain...it is to get in and get involved and make them see the worth of more customer focused services...that is the way forward and that is the way I intend to play it.'

Nicholas has been having shiatsu massage on the NHS which 'is exactly the opposite of the vast amount of grief you get if you try and get it out of any of these organisations'. He has found shiatsu very effective at keeping his muscles going, for relaxation, for the damage that has been done to his back as a result of caving and for the neuropathic damage caused by the AZT.

'I am a firm convert to...complementary therapies, because it *does* complement the other more aggressive, chemically based therapies' and he regrets the move away from that kind of service within HIV organisations.

#### *Attitude to virus*

Nicholas is much more wary about what his body is capable of, but having said that he is a lot fitter and more resilient than many other potholers and he would be fitter still if he lived in the country where it is easier and more pleasant to go for a walk, run or climb. Although he is fit, he is aware that fitness can actually suppress his immune system.

In terms of relationships, Nicholas will cut people out of his life quite ruthlessly if they don't react well to the fact he is positive. At first he was quite selective in who he told but now he is more open: 'I had the amusement of telling the directors at work that their chief engineer has been HIV positive for 5 years'. He still finds that occasionally people are anxious about the risk of infection but Nicholas wouldn't regard it as a negative response to be asked about infection risk - he feels people have the right to be reassured.

'Public health campaigns have been very focused towards specific groups because of the latent homophobia in society' so many people still aren't aware of the basic facts of HIV.

Nicholas on two occasions has nearly killed himself caving and he is aware, from his own experience and that of others, that he takes part in what is a high risk sport, 'so I thought I was well anaesthetised to this life-death thing, but actually it's not true...when you do have to face up to the fact that you are going to die, potentially fairly horribly and potentially far earlier than you'd anticipated, then yes it does have a devastating impact.' Before he got tested he had thought he had faced mortality but a positive result was very different.

Most of the time when you are caving it is just as safe as walking down the street, but there are occasions when it is 'dodgy', especially when the weather is bad and when you're tired - there are occasions when you realise that you are treading a risky path and you can have a lot of narrow misses, 'you are aware of it and you deal with it, and you make your own luck'. HIV, however, is different, 'when you're living with an illness, where the assumption is that it will eventually kill you' this is a different sort of facing death than making decisions about risk when you are caving.

'The feeling on the street has always been that if you can cope with it you'll live, and if you can't, you'll die' and Nicholas has seen that for himself - he has seen people who couldn't cope with their status deteriorate rapidly.

### *Spiritual beliefs*

Nicholas was brought up within a churchgoing family where the local church was very much integrated within the community. His early experiences of church were positive.

Through his degree, Nicholas has a reasonable understanding of the recent thought within physics, genetics etc. 'and it's hard to find religion in that'. He is basically sympathetic towards religion because it was part of his upbringing, 'but I can only believe in it as a set of cultural and societal beliefs...I don't want to downplay other people's beliefs but I don't believe the literal God mechanics of it'. One of the biggest obstacles, however, to any religious belief is the intolerance shown by the church towards gay men.

'The sheer level of intolerance towards minorities, other religions, is unacceptable and I will have nothing to do with any religion...I would regard them with extreme caution and it may be necessary for society to defend itself against these people. I would regard the extreme religious zealots of any religion in the same light as other generations would regard fascism and communism...It may be necessary at some point to push them back into the Stone Age from whence they came...

...Politically very much I'm very much the middle of the road...this is the only part of me...where I would probably diverge from standard political opinions in this country...it's very different from the religion I was brought up with which basically was very tolerant...

...In a city religion is something which you just don't see' and what there is seems very polarised and certainly not integrated within the community. In a rural area, Nicholas feels that people mostly claim to be religious and everyone will know the local priest. A communal event invariably involves the church in a way that it doesn't in the city. 'Religion in the country has to be a bit more circumspect with those it chooses to exclude.'

### *Living in London*

In many ways Nicholas would like to go back to living in the country, especially as most of his free time is spent in the country, but work ties him to London. In the future, however, he might well move out of London, 'and go and live below a mountain somewhere'. If he moves out of London, a rural community will have to cope with him living as an Out gay man:

'Having come this far out of the closet there is no way you're going to put me back in it - it's too small!'

Ideally he would like to live in North Wales - he likes the area, many of his friends live there and the cost of living is low. It would raise issues, being ethnically English in a Welsh area and being gay. In other ways, having grown up in a rural area and having spent a lot of time in the country, he is well aware of what it means to live in a rural area - 'I know what all the farming bits are called!'

## *Work*

Nicholas originally trained as an electronic engineer but ended up working for BT research. He worked there for 5 years doing a lot of early internet technology. For the past 5 years he has worked for a small company but he has reached a bit of a dead end as far as career development is concerned; the prejudice towards engineers, treating them as blue collar workers, prevents the company from making him a director. He plans to look for another job in the near future. He is in a sphere which is very much in demand so finding new employment won't be difficult.

On the other hand, he doesn't want to be working himself into the ground in 10 years time. If he did contract work, he could charge a lot more for doing the same sort of work and this would give him a lot more options, even not to work for most of the year, but Nicholas says in many ways he's not that mercenary and he actually quite likes having a permanent job.

'I've never been one to play management politics' and Nicholas thinks that this ability to distance himself from work place stress has enabled him to continue to work since his diagnosis. His position within the company, in spite of his current poor relationship with company directors, is also strong:

'The boot is on the other foot. I can basically boot them around and they have to say 'Yes sir, yes sir' and that makes a lot of difference to being out and positive in work'

Nicholas can afford not to work for 6 months 'and not piss the bank off too much', to do contract work on a very part-time basis, and this puts him in a very powerful position with an employer. It's still in his interest to work because he enjoys it and because it enables him to stay in his house which is a massive investment.

'The criterion I have for continuing work is that it should not hurt my health'

One of the results of having chickenpox is that Nicholas is being advised to start treatment again. One of the drugs he might start on is 'efavirenz and the side effects might well put him out of action at work for a month 'which would scare the shit out of the company directors...It's the nearest you get on the NHS to being put on Class A drugs...apparently there's a black market on them, they're that powerful!'

Nicholas feels that the permanency of a job is attractive but short-term contract work can be so much more lucrative and will have the tendency to snowball.

## *'Gay community'*

'In general the gay community doesn't...have the lobbying power of other communities' partly because there aren't a lot of Out older gay men and Nicholas feels this will change as the first post-liberation generation become older. These people can then adopt the role of community leaders. Nicholas went to the vigils after the bombing of the Admiral Duncan and noticed a strong sense of community, and there is a sense of community within the HIV sector. But there are also more positive communities which are the communities of the scene, the people who will go to the same club year in and year out:

'I haven't been to Trade for over two years but I could walk in there tomorrow and be recognised and people would say hello to me...it's a commercial community and almost a community of the excess, but it is a community...and it will develop.'

Nicholas believes that virtually all gay men under the age of 30 are Out and this will have an increasing impact on society. There will be a clearer awareness of the diversity within any group of gay men - a realisation 'that you can be a gay engineer'.

#### *HIV and relationships*

Nicholas doesn't feel that HIV has had much of an impact on his sexual relationships. He has not experienced any sexual dysfunction and he has always felt able to be open about his status; 'my view is that if you can you should be positive about it but it's not wrong if you're not'. He only once has had a bad reaction as a result of divulging his status 'and they basically got a lecture'. Nicholas believes that this is very different from 5 years ago when it was quite rare for people to disclose their status to their sexual partners.

#### *The future*

Nicholas is in better health than he was when he was tested and so a bit of him wants to push HIV to the background, but on the other hand he feels it is important to continue to 'plug away at it' because his health could potentially deteriorate rapidly.

'I am doing my small little bit for tolerance just by leading my own life, by example and that brings a certain pleasure to me...We're only asking to be treated like anyone else and we're a long way short of that'

## **Participant 23 - Michael**

Michael is a 47 year old man who was born and brought up in the Midlands. Most of his early years centred around school before he went to University and then further postgraduate training. After becoming professionally qualified he lived once again with his parents until he was 25 when he moved to London - a move more related to his sexuality than his career - and he has lived in London ever since. He stopped working in 1994.

### *Growing up and Coming Out*

Michael's teenage years were very miserable. He had a 'liaison' with another boy at school 'and we used to do this and that with each other and this was all strictly confidential...like a lot of public schools...It put pressures on things at home because you're being judged as to why you haven't got girlfriends, family are saying this and that, and I'm an only child as well'.

Michael was not Out at university which in retrospect feels quite odd to him but given that it was the early 1970's, he was afraid that being open about his sexuality would be detrimental to his future career prospects. For the whole of his final year at University he was in a relationship with an older man in a nearby city and keeping this separate life from his friends at university placed quite a strain on him. 'It was three years of trying to keep things under wraps, which really wasn't terribly acceptable...I was having to construct a lot of tales, which was a very unsatisfactory way of carrying on...it's difficult in retrospect to say how one would behave differently...'

When Michael returned home after his postgraduate training, he decided that he was no longer prepared to live a lie with his parents. His partner who he had been seeing through university was putting pressure on him to move in which would have limited Michael's career prospects. Michael felt he owed it to himself to give himself the best chances with his career and the relationship ended. 'So I was fed up generally...and my mum said to me, what's wrong? By this stage she'd realised there was no girlfriend being brought to the house, she went through a process of elimination almost...I think at that stage you're concentrating more on your own emotions, rather than working out the emotions of the person you've spoken to but I don't think she was surprised. She was pleased that I'd been able to speak to her about it, that I'd been honest about it.'

On the other hand, Michael's father was harder to tell. He was an ex-soldier and held very conservative views; 'he wasn't a very intelligent man...You could very rarely have a discussion on moral issues or pros and cons...I never got on with him at all. His view would be sweeping generalisations...

...I used to sit there thinking, how have I been produced?...My mother, with due respect to her, she had a very poor education and I suppose my father did as well, but they'd gained enough money to put me through public school...and obviously I had learnt a lot more things...there's this thing about intelligence, whether it's inborn or acquired or whatever but my horizons were so much broader than their horizons were.'

There was a lot of pressure on Michael to be 'the perfect son, particularly as he was an only child, and in many ways he had fitted that role through school. He did well at sport, he excelled academically 'and really if they had planned a route...for my career, you would think they had done all the right things as far as they were concerned, so they were wondering what they'd done wrong, and being an only child you can't judge it by having another brother or another daughter who might not have been gay...'

When Michael told his mother she said that she didn't want his father to know as he was at that time under a lot of pressure at work: 'one would have thought that the emotional health of your son would have been more important, well not more important because you've got to put the bread on the table, but at least something that ought to have been taken into account. I was...put out by that...

...But then again I was 21 and I was making my own life. I had a lot of friends...so it wasn't as if I was sitting at home every evening with my mum and dad watching the TV, I was leading my own life...'

In the end Michael found out that his mother had discussed the issue with the local vicar who told her that as long as Michael was happy, then there really wasn't a problem. It was then she decided to tell his father. 'It transpired later that the vicar left his wife and 2 children to live with another man!'

The way his father was told was that Michael's mother stayed at home with Michael, his father was sent to the vicarage, the vicar told his father that Michael was gay whereupon his father returned to the house. 'I honestly can't remember that day at all, it's as though it might have been blanked out of my memory, you know how certain days you have a perfect recall, and one would think I ought to have a perfect recall of these 2 days, but I think they were quite a shock emotionally and I think I blanked them out.'

Michael's father had a fixed opinion that being gay was a matter of choice and Michael could 'make himself' heterosexual if he chose, whereas his mother took the view that he must be gay by nature.' His father was further confused by the fact that Michael didn't fit the gay stereotype: 'I was quite masculine...I wasn't camp and effeminate and waving my arms around...There's the whole range of how gay men are but I wasn't the stereotypical gay, winsome individual who didn't like sport.'

Michael felt very let down by his parents although now he feels that, if he were to have a child, he would prefer that child to be heterosexual rather than gay: 'Because it's easier in life, not that that's a homophobic thing to say, one hopes, but I think most gay men, gay people, would tend to think if someone's going to have a balanced life, an easier life, and have a wider choice of partners, which is quite a lot to the point ! If one is gay you narrow the field down enormously...I never understood why people say 'I'm proud to be gay' It's fair enough to say 'I'm not ashamed to be gay'...To be proud doesn't quite sit with me.'

By the time he was about 26, Michael was living in the middle of London and was out at work 'and I had a fabulous time, socially and all the rest of it.' It was not till



much later, however, that the rest of Michael's family found out he was gay. Michael's mother decided that she didn't want the rest of the family to know and this lasted until Michael was 35 when he was having a relationship with someone and couldn't bring him to any family gathering so he insisted that his mother should tell them and in fact the reaction was in general very positive.

### *Moving to London*

When Michael reached his mid-twenties, he decided that if he was going to have to leave home and set up house on his own he might as well do it in London. Already he would travel down to London or Brighton most weekends - there was only one local gay pub - so although there was much less of a gay scene in London than there is now, there was much more available than there was locally. When it came to it, however, the move wasn't an easy one; he had been treated well by his work-place and it was sad to go, and his parents found it hard that he was moving away.

### *Michael's father's death*

'Sadly my father died in 1980 only a year after I moved to London. I don't think one ever quite gets over it. He had a heart attack and died on the spot, just like that. It meant that things were never resolved with him, and it would have been nice had they been resolved. I was just finding my feet in London. Had he been round a bit longer, it would have been nice if mum and dad had been able to come together and stay with me, and for me to resolve things with my father. But as it is I still carry with me quite a lot of resentment and annoyance that he would not accept me for what I was. I can remember on the evening when my dad died, he died in the local club in the village where we were and he was having a game of snooker. The next door neighbour was playing snooker with him and came into the house and switched off the TV and said 'D\_\_\_'s died'. I remember saying to mum in the garden, because she was in a terrible state, 'He did love me, didn't he?' and that was quite a problem I think, and even though mum and dad knew for 6 years... there were a few boyfriends who'd come for tea, I remember one guy stayed the night which caused a terrible problem afterwards.'

### *Life in London*

Michael lived in a few different places in North and West London and 'I had the time of my life...I was quite happy about the way I looked, I was quite happy about my equipment, so to speak, I was in a good job, there were no problems at all. If I wanted to go out and meet somebody, there really weren't any problems. We used to joke about your dance card, and you'd build up your dance card through the course of the evening and then you'd make your final decision... I enjoyed sex and had a lot of sex.'

Michael went out a lot but he also worked hard and was disciplined about managing a job in which he had to be reliable and on the ball.

Michael feels that being gay prevented him from having a more successful and lucrative career; he didn't attempt to climb the ladder at work because he believed that he would have been more stigmatised: 'I became a partner by the time I was 30, so I'd done that bit...and I had my BMW and my American Express card and expense account and I was living off the back of the Thatcher years of house prices booming and remortgaging and all of that, but had I moved up another gear earlier, I think that would have been much better.' On the other hand, Michael was reasonably happy with the amount of money he was getting and the lifestyle this enabled him to have.

## *HIV*

Michael remembers the herpes scare in New York at the end of the 1970's but at the time STDs were regarded as a mere occupational hazard. In 1985, however, his best friend's boyfriend died of an AIDS-related condition: 'He was 109<sup>th</sup> on the total of people who had died in the country from AIDS...He was diagnosed with HIV in the September, came to my birthday in the November, didn't look very well and didn't eat very much and he was dead within 6 weeks. He had everything under the sun - pneumonia, meningitis...Pneumonia got everyone in the early days...I'd actually slept with him, so from that stage onwards I always knew it was a possibility.'

'Even in '85, it certainly wasn't standard practice to take any protection, it certainly wasn't with me or with the circle of friends I knew...I don't think my lifestyle changed particularly, as far as sexual partners were concerned, I had a fairly rampant appetite and I enjoyed sex and it didn't stop me from having sex at all. Probably a year or two after that, you tended not to do anal sex...to be honest you tended to avoid people from America, people from America were persona non grata really ... so basically the deal was life just went on and you hoped it wasn't you'

'People were starting to die. When I moved to London there were 5 of us in a flat. ... Of those five, two have died, another one is HIV+ and the fifth one I've lost touch with, so four out of five have either died or are positive and the fifth one is almost certainly positive and I think he's died as well...Where we used to drink in a pub...on Sunday afternoons - they're all gone; all of that circle are all gone and I'm still here. It's very sad to think that that's happened.'

Michael thinks he was probably infected in 1985 but his life was going well, he didn't want to know and he saw no point in knowing. 'In the background I knew that probably the clock was ticking, that if friends around me were dying, particularly people I'd slept with - I'd always worked on the basis that I was going to be HIV positive at some stage. I never really saw myself surviving it. There was no point having a test and having it confirmed because there were no drugs, it would have affected my career and I would probably have gone off the rails, and I didn't have any symptoms. Now it's very different, there are good reasons as to why people are tested now because of early intervention, there are obvious health benefits in doing it but then there was no point in knowing, and it affected life policies and insurance and jobs and all the rest of it so I thought I'll just carry on regardless. I took reasonable protections I suppose, I may have slipped up now and again but I was aware of what I should be doing and what I shouldn't be doing.'

So Michael carried on working, earning more money and taking weekend trips to Amsterdam: 'I'd remortgaged the house and prices were going crazy and life was going on and people were dying all round me and I thought you'd just got to sort of carry on - what does one do? I suppose...I was working on the basis that I was going to do everything I wanted to do because I thought probably that my time would come...it was rather presumptuous to think that you were exempt from all of this...'

In May 1994 Michael became ill with a high fever and night sweats. After two weeks he ended up going to A&E where he was given antibiotics and sent away although he

was actually suffering from pcp. After another week during which he had practically collapsed, his friends persuaded him to go to the GUM Clinic and they diagnosed pcp.

‘The friend that came with me was my best friend at the time...we were just very very good friends and I was left alone with him in the room. He was HIV positive so I had lived with him being HIV positive without symptoms for the previous 5 or 6 years. ..The doctor thought it was some big emotional thing but I already knew.’

Although it was a foregone conclusion that he was HIV positive, he didn't want to have the test at that point because he didn't want his employers to know. He had actually gone back into the closet as far as work was concerned because jobs were once again becoming scarce and he was less attractive to employers at 40 than he had been at 30. He got back to work and decided that, in order to put himself in a strong position, to buy a house and get a mortgage:

‘Three or four months after that my heart really wasn't in the job and my health on paper was very poor, my CD4 count was 20 - my doctor said I could expect 6 months to a year of decent health and then another year and that would be it...So I really faced with...having to shut up shop and get life organised. I think mentally I was very strong willed and strong minded...It was as though I almost split in half in a schizophrenic sort of way...I was very systematic and organised, did a lot of research on the financial implications of what to do...and how to organise things, and it was though I was looking down on myself from above...It was a dispassionate way of behaving but I've always been a loner, an only child, independent and I've always worked independently and I suppose that was the way I'd led my life without interference from other people, so I felt able to do it all that way.’

Michael's CD4 count was below 50 and at one stage went down to 8 ‘and there was the awful things of dementia and blindness and all of the other stuff, the whole list of things that I was susceptible to, and fortunately I didn't get anything at all...it must be genetically that there are guys like me...there must be a lot going on in my immune system which has been to my benefit, plus I think my lifestyle...’

‘...So I got my stall set out to die, which might have been rather pessimistic...but I think one has to get things organised...there's a difference between realism and pessimism.’

Michael bought a house, gave up work and claimed the full rate of benefit, so physically he was securely set up. Mentally he found it harder to adjust.

‘My father was only 63 when he died...and a lot of my friends were dying, my best friend was 32 when he died and another one was 25-26, and I think it was around me all the time so I was mentally adjusted into dying, so it was quite easy to get things in order. And then you really were living for the moment.’

In some ways this time was very hard for Michael but in other ways he was able to be quite focused whereas now his life and his future are a lot less clear, and his health continued to be extremely good once he had recovered from the pcp; he had AIDS but nothing had changed.

### *Treatments*

Apart from AZT, all the drugs which Michael has taken have been on a named patient basis as part of a trial, and he describes himself as 'being on the crest of a wave' in terms of treatments. 'Now having reached this stage, I'm quite satisfied that I will have a reasonable life expectancy and I'm extremely confident that I'll be around until I'm 70 or 80. But that's only happened over the last 3 years.'

### *Living with the terminal/chronic dichotomy*

With an AIDS diagnosis, Michael was automatically passported onto the highest rates of benefit and now he is in a position where it would be a significant risk to give that up. Although in terms of his day to day health he doesn't seem to qualify for those benefits - and one of his uncles has recently implied he is a scrounger - he is very reluctant to do anything which would jeopardise a stability in terms of health and financial security which have been hard won. He also argues that in fact he would cost the state more money in treatment if he were ill than if he is well and on benefit.

'Somebody in my position who's health has been so bad on paper should have different treatment from the DSS compared with someone with a condition that stops them working...there's a difference between a life threatening condition and a condition which stops one from working, and there's no distinction made in the system...I would be very happy to work in a paid job...if my situation could be frozen...In an ideal world I would like to have the benefit of being able to get back to work but to still have control over my life. It's very important to me that my health doesn't deteriorate because I've seen friends carry on working and got worn out...Even though I'm not fulfilled in my life by any means, the benefit thing is really quite a problem...You're dealing with officialdom who are well...they assess you and then carry on with their lives, but it's the core of my existence...'

'Work...would give me some structure...when it gets to 6 o'clock I feel normal again, I don't feel normal during the day. When it's 6 o'clock and the news comes on and people are going out in the evening, it's what ordinary people do, so I prolong that a bit by watching the television till 2am or I go out late, so I end up not getting up until 10.30, 11.00, so my day is skewed around...'

### *Attitude to life*

Michael has lost most of his long-term friendships and finds it difficult to form new ones so his daily life is reasonably solitary. He particularly feels the loss of one friend to AIDS who 'knew all about what was going on and he and I were always a support to each other, it was always he and I and we didn't need anybody else. He was as close to being a lover as a best friend could be, almost like a soul mate. I think a lot of people have soul mates who are not their partner, whether they're straight or gay or whatever...We were very close on all levels, plus the HIV.'

Michael enjoys reading and has a large collection of history books: 'I actually wake up feeling happy that I have a choice about what to do during the day, it may sound trite...but it's such a bonus actually to feel as if I've got a day ahead of me, I'm feeling well, I'm in the middle of London, there's lots of things to do...I have a choice about what to do with my day, whereas everybody used to say I'd be dead by now or in a wheelchair...There's a difference in threshold...people in 'normal' life have a very

different set of objectives...to me...you start to look at life very differently, as in what's important to you and what isn't.'

Autumn is a difficult time of year for Michael, with painful anniversaries and a climate which he finds depressing, and he feels quite isolated at these times. He sees his mother reasonably frequently - they are both season ticket holders at a football club - but he doesn't always feel able to talk to her about his more difficult feelings. He has a close relationship with his mother but sometimes she pushes him to do things he doesn't yet feel ready to do and he also feels he still tries to win her approval.

It was at a particularly low point that Michael decided to join a positive Gay Men's Group 'and that was really quite a life saver. I was really very low. Had I not done that I was really getting quite down, not in a suicidal way...but I could almost understand...it wasn't suicidal but I could understand how people could gradually wind themselves down into such a low state'

Michael has found the group enormously beneficial; he appreciates being able to talk with people who have been through the same experiences and are dealing with the same difficulties. He regrets not having joined such a group earlier and feels that such services are inadequately promoted and supported.

#### *Back to work?*

Michael has decided that some doing some voluntary work might be a way of seeing how his body copes with a working day without losing his benefit. On the other hand, he is unlikely to earn a salary which would make him better off financially than he is on benefit.

Coming off benefit would mean having to sell his house, a move which Michael is reluctant to make, and to sell his house would mean releasing money which would increase his options but would mean he would lose his entitlement to Income Support.

'I really don't want to be how I am now in 10 years time. I almost feel now...whereas I was very protective of myself and risk and wrapped myself in cotton wool, I almost feel now that I'm at the stage of risking it, and if I have 10 years of doing something different and drop dead in 10 years time, I'd rather do that than trundle along...but it's a difficult concept...from having worked out that you're going to die, to then get through that, to then move on to a different stage of thought, into now risking it all again. For a long time I wasn't risking things, for my health, and now I think perhaps I need to risk all of that...'

'...I've got to risk something somewhere. I think perhaps I'm too intelligent, I'm cursed with thinking. I've got a lot of options which is nice to have. I could have been in a council flat in Tower Hamlets...If I look back in 10 years time and I'm in the same position, I'd feel it was a waste. I feel it's a waste now, I'm wasting time when I've been lucky to have this time and I'm not doing anything...constructive with it.'

#### *Bereavement and friendship*

Michael's friend's death was profoundly shocking:

'it's such a foul way to go. You lose all your dignity, the wheelchairs, the carers, the bedroom's full of wipes, tissues and pills and then you can't take the pills because you're not well enough. All of that, I just cannot face in my mind the prospect of that happening to me...'

'...We had the same sort of sense of humour...You know when someone will be amused by something that you're amused by, whereas somebody else wouldn't think anything of it. And of course the shared experiences in the past which you can't then relate...you lose that ability to reminisce about happy times, it's like a chunk of happy times is removed as well, because you can't share those again.'

Daniel had bought a house near to Michael in order to look after him but in fact it turned out to be the other way around. He gave up fighting which Michael found very difficult to accept and he still feels that if he had continued on treatment he might still be here today: 'I was having to fight for him to try and get the right treatment and he'd had enough of it...but indinavir and things have turned a lot of people round from a very poor state of health...you gradually build up again...he was just on a plateau going down to a lower plateau, then he'd stabilise and then go on to a lower plateau and never get up those steps again...He didn't have a decent quality of life at the end...'

Since his death, Michael has also lost other friends who were friends of Daniel's. He doesn't want to get in touch with them because he doesn't think that they would want to be reminded of Daniel through him.

#### *Other lost friendships*

Michael has lost other friendships, because he is simply unable and unwilling to maintain the sort of lifestyle they expect:

'When you don't have much money you can't keep up with people who are going away for the weekend, eating out, going to the theatre and going and spending £40 on a meal afterwards, and I just can't do that any more and you end up losing them... then you start to resent friends because you think they ought to be paying for you, and then you think what would I do in a similar position, perhaps I would be a bit more generous than they're being, and everybody's talking about money, how many shares they've got, and I suppose I hide away from a lot of that because I don't really want to have to deal with it. Should I deal with it?...I think in the end you get yourself out of situations you don't feel comfortable with...You know when you have a piece of wood and you whittle away the bits that you don't need, you end up cutting away an awful lot of stuff that is painful to have to do. There have been friends of mine who are more friends because you're going out drinking the night away or going out all night and they'd be doing drugs...things were going in directions which although I enjoyed weren't really what I wanted, so you have to try to cut them away, but then you cut away so many people and situations that you become quite isolated. I think I have to see it as a positive thing to do, because I think I have to avoid being in positions of stress and not being comfortable.'

Michael feels it is important for him to spend more time with people who hold other values, people who are happy 'to have a walk through the country as opposed to having an expensive meal in Mayfair... it's sort of a re-education of one's lifestyle.'

### *Recent health*

Although on the whole Michael is in good health, two years ago he was diagnosed with diabetes as a side effect of the protease inhibitors and he now has to take insulin and be careful with his diet. His viral load has now been undetectable for three years and his current CD4 count is 420.

‘HIV makes you feel not normal because you don't bother about the things that other people bother about. It makes you more isolated because other things seem so trivial.’

### *Current relationship with his mother*

Michael is anxious not to cause his mother extra stress and also feels responsible for her quality of life; they are both close but neither wishes to be too dependent on the other.

‘It's a complicated thing...I think I would have taken more risks if it had not been for her, and she gets annoyed and says well you must do what you want with your life, but then I feel it's the most appropriate way to lead my life. ..I don't want to hurt her unnecessarily. She says you're independent but I'm not independent, and there again she isn't a dependent.’

### *Sex and Relationships*

Michael hasn't had a long-term relationship for some time, and would like to have another relationship, although he can only envisage it working with someone who was also positive. He has found it hard to meet people who are on the same wavelength as he is and he also wonders how much his very restless sleeping pattern would affect a relationship

‘I was never very good at real sleeping with people at the best of times, whereas some people like to have someone around them in bed...I enjoyed all the intimacy and everything else but I was never very keen on being wrapped round somebody and vice versa.’

Although Michael feels a responsibility about not passing on the virus, he does have casual encounters where he feels it is up to the other person to ask the question: ‘I think most gay men work on the assumption the other person is HIV positive. I think that's the only way you can practically work your life. ..Even if you ask the question people can lie to you...I've always used condoms. I've had unsafe sex on occasions, when the other person has made it clear that they don't want to use condoms but I very rarely do that now, I may have done so in the early days because then HIV was HIV, we didn't know about the different strains.’

Michael feels that there is a band of opinion, ranging from one extreme which is that you should disclose your status immediately, to the other which is that you can do whatever you want. As far as Michael is concerned, he is not prepared to stop having sex but he also doesn't want to feel or to be irresponsible.

‘That's why I'd feel happier having a relationship with somebody who's HIV positive ...also both of you would know that if your health were to fail you'd feel it was part of the script...It's only now that I feel freer of all the baggage that was around me to actually feel I'm a person that somebody might like to have a relationship with.’

because you've got to like yourself and be happy with your own environment to actually feel free of all of that.'

### *Football*

'I find at the moment one thing that keeps me reasonably sane is I enjoy watching football. Football gives me a lot of structure in my life. I support Leicester City who have been doing very well over the last 4 years, which has nicely coincided with my malaise. If I've been out on Saturday night late, and get in at 3-4am, get up at midday, and I'm quite happy to watch two games of live football on television, which I love doing, and I would hate to be in a relationship with somebody who hated football. So I've got into a groove. Ideally an HIV positive football fanatic would be an ideal partner. Nobody likes football very much, I mention it to people who all hate sport, but that sort of thing keeps me sane. And I enjoy current affairs, reading The Times and watching serious programmes on the TV. I enjoy Georgian and Victorian history and biographies. Something like being a guide at a National Trust property...that sort of thing, and those things aren't enjoyed by many people, but I do enjoy having a drink and going out to the bars and dancing the night away and all the rest of it!

### *The future*

A tentative plan is to do some voluntary work to get back into a routine of working, and then maybe to sell the house and get somewhere smaller, invest the money left over and use that to subsidise an income from a job in the HIV industry.

### *Services*

Michael is happy with his hospital services which have been one of the reasons he has stayed in London. Particularly when his health was poor he felt it was vital for him to be able to access state of the art treatment. This is less vital now, partly because of his improved health and partly because of the growth of the internet which has eclipsed distances. He tends to use his clinic rather than his GP and his relationship with the staff there is good.

One of the criticisms he has of hospital services, however, is that people's general mental health isn't addressed. 'That might be the impression that I give off that I'm sorted out and independent and not needing it, perhaps if someone else presented themselves as being a mess he would give more time...'

Michael is more critical of the counsellors in the HIV industry - he feels that it is people who are HIV positive themselves who are able to provide support because they can draw on their personal experience and it is for this reason that he feels it is vital that more positive people gain employment in the field.

Michael feels that there are too many HIV services in London and it is appropriate that some of them should close. He feels that the expectation some people have that HIV positive people should receive free services such as complementary therapies etc. is no longer appropriate: 'There's a lack of sympathy that will happen in the end because people will say well you should be doing a little more for yourself.'

### *London services and living in London*

Michael is sure that he would not have received such good services, either from the medical or the voluntary sectors, if he had lived outside London. In London he has



been able to participate in clinical trials and be rigorously monitored, and he feels if he had lived in a rural area he may well not be alive today.

‘I think people in London have more drive than people in other parts of the country, if I look at people who are gay in [his Midlands home town], all the boring ones with no drive or force about them stayed ... I think London attracts a more dynamic kind of person who's going to be more dynamic about all levels of their life, whether it's health wise or social wise, personal development. Education obviously comes into it - people who live longer tend to be those who are generally more intelligent, I suspect. I have an avid thirst for information about things, that comes with intelligence and being in London, I think...it's almost a death-wish to live somewhere...isolated.’

#### *Staying informed and being in control*

Michael feels that he is more able to stay informed about his HIV living in London. He has also done a lot of research on the internet, particularly about drugs he is taking on a clinical trial basis:

‘Things like internet access is very important and you only get that with money...You feel as though you get a bit of respect back again’

#### *Daily life*

‘I feel very much in control of my life...so now it's up to me to do something with the life I've got...I've got too much time to worry about what's not right. Going to work is an easy way of living because you don't have to think about anything, I find now I have to make sure that I think about doing things I enjoy - going for a walk or reading the paper...There are so many more choices one has to make if you are not working. You have to be happy! The pursuit of happiness is a 24 hour pursuit of happiness, whereas when you're working it's like a weekend pursuit of happiness. I think that's what makes me feel quite stable - there's no real challenge in looking forward to the weekend. It doesn't really matter, and that's another thing that isolates you from ordinary people...This is what I'm about to sacrifice, to have a week of disciplined work....’

‘...Nobody sat me down and gave me advice as to what to do, I'm so lucky that I'm intelligent so I was actually able to do it, whereas other people in my position could have just drifted and ended up in a council flat at the whim of the council and not having control...I think control is the really big thing in my life, and in most people's lives - more so when a big chunk of it is out of control, you can't get rid of the HIV, whereas in ordinary life you're told that if you go to school and work hard and get your exams, you can do this career and that career...’

‘...I think I'm a bit too much of a perfectionist sometimes. I think I want a goal that's achievable that's a sensible goal to achieve... I'm in sort of free fall...I'm more floating, floating upwards...’

## **Participant 24 - John Percy**

I interviewed John under different circumstances from other interviewees and this affected the way the interview ran. The previous night John had made a suicide attempt and, under these circumstances of crisis, it felt important to discuss what was going on in that moment than to stick more rigidly to what was already rather a loose interview schedule anyway. This means that we covered some areas in more depth and didn't discuss other areas which I may have covered more fully with other interviewees. John wanted to be referred to by his full name.

John was diagnosed in 1999. At the time John lived in a rural community in Scotland and was very active in the HIV community there, opening his own drop-in in Skegness. Since diagnosis 'my whole life style has changed, my whole attitude has changed.' He has had his status made public knowledge and as a result has been both physically attacked and has lost his family, his friends and his partner of ten years.

### *Diagnosis*

John had a brain haemorrhage and was rushed to hospital by air ambulance to Sheffield, being resuscitated four times on the way. It was as a result of attempts to match his blood in order to treat him that he was diagnosed HIV and hepatitis B positive. At the time of his diagnosis, his blood counts were extremely poor.

### *Services*

John is angry that he has been refused as a volunteer by the local HIV organisation where he lives now although they still allow him to participate in fundraising activities, particularly around World AIDS Day. He has also organised a tree planting event locally.

When he lived in Manchester he was attacked but the local HIV agency accused him of lying both about his health and about the attack. He has been accused of breaking people's confidentiality but John says this is something he would never do. He has, however, been in a situation where another service user has made a public announcement about his status in one of the gay clubs in Manchester. His Motability car was broken into twelve times which has had severe financial repercussions on John. He is not able to access hardship funds:

'But what I have to do with my money is to go out every night to be in company which means a long drive to a night club...I stand on my own and just ignore people but just the sense of being in a group makes me feel OK. I go and I dance and I dance and I dance and sniff poppers galore to kill the pain.'

John is about to get his utilities cut off because he cannot pay his bills. The response from the local HIV organisation has been 'you need to start controlling your life and you need to start controlling your attitude and you need to start controlling your financial affairs better, but they don't want to put themselves in my shoes.'

At Christmas last year, John describes how all the staff at the local agency went for a Christmas night out but he was left on his own and unsupported all over the Christmas and New Year period.

There is a policy that volunteers don't mix with clients:

'I'm the only person who comes into the drop-in, the rest are volunteers, and they all sit there chit chatting they don't say how's your day been....they think they know all about HIV, but how can they unless they're HIV positive themselves?' He feels that HIV groups should be facilitated by HIV positive people and that it is wrong that volunteers can access money but clients can't access hardship funds. He feels that the money which the government gives to HIV simply goes in wages to non-positive people. He says that people tell him to keep going because he can make changes but he feels that he can't beat the people who get wages - the whole industry now relies on status. When he dies he wants his belongings to go to an HIV positive individual rather than to an organisation.

'They do meditation classes and all that for the volunteers but clients aren't allowed'. He says reiki and massage are also only open to volunteers. He used to be a buddy in Scotland but he doesn't feel that he could accept any volunteer as a buddy because he's worked with them as colleagues and he doesn't feel that they would be able to support him anyway.

He has even gone to the lengths of going to the newspapers, just to raise awareness of his housing needs.

John's GP wants him to be admitted to a London hospital long-term but John feels that, although there is nothing to keep him in the local area, he would lose his independence if he was admitted to hospital.

A social worker John had in the past offered him cannabis to calm him down whilst he was on duty, and then he befriended John's partner and introduced him to someone else, and then John's partner (who was negative) left him for that other person. John put a complaint in but he wasn't well or strong enough to pursue it. He currently has an appeal against the benefits agency which is lodged with the Ombudsman and he feels he should sue the hospital who treated him for his brain haemorrhage as he feels that they were negligent, but again he doesn't feel strong enough to do it.

John attends the local clinic where there is one consultant who is a GU specialist rather than an HIV consultant and a health advisor.

### *Family*

Both John's parents are dead, but his other family have written him letters to say that they don't want anything to do with him because of his status.

### *Current feelings, suicidal thoughts*

The night before I was due to meet him, John took an overdose because he 'wanted to die with the little dignity I've got left'. He begged the police not to take him to hospital because he wanted to rest and he still feels like this. John says that he simply cannot see through another day and that the loneliness is killing him.

'My body's tired, my head's tired, my heart's dead...HIV's ruined my life...I don't see a way through any more...I don't eat any food now because I'm not able to stomach it'

John feels he is able and wants to help people and feels he has a lot to offer. He is a qualified massage therapist and a qualified healer:

‘I’ve got a lot of love in my heart, and a lot of love to give somebody and a lot of care to give somebody’ but he doesn’t feel he can get any support. John has decided that he is going to stop his HIV treatment because he simply doesn’t want to continue. He says it is impossible to access support even from the London-based agencies because he cannot afford to make the ‘phone calls:

‘I spent £20 on my ‘phone last night ringing National AIDS Helpline and just got nowhere, so I sat in front of my coffee table, took my mum and dad’s photograph off the wall...and swallowed all my tablets.’

John then rang the police and told them what he had done. He wouldn’t give them the address but they recognised him and knew what street he lived on and so they broke his door down and took him to hospital.

‘I’m frightened of staying alive, but I’m also frightened of dying, and that’s why I ‘phoned the police...I just feel I’m letting everybody win, and I feel I’ve got so much to give’

#### *Attitude to status*

John thinks that in fact his diagnosis may have been a false positive ‘and if that turns out to be the case I will sue everyone that’s involved’. He has had an extraordinarily high CD4 count and thinks that because of this he may in fact be negative.

Whereas he used to be proud that he was able to be open, now he is ashamed to be a gay man and ashamed of being HIV positive: ‘I wish I’d never opened my mouth now, and I wish I’d been deceitful with people’.

John feels that he has tried to turn his anger outwards and express it constructively but each time he has tried to do so he has been thwarted so now he is turning his anger in on himself.

John is always very careful to have protected sex but he says that many people don’t seem to care and if all gay men were tested, the number that are HIV positive would be shockingly high. He is also angry that HIV is classed as a chronic condition even though people are still dying as a result of AIDS-related illnesses.

#### *Health*

John has lesions on his feet which haven’t been diagnosed definitively. They are beginning to weep but John says that the health professionals aren’t taking any notice of them even though he is finding it very difficult to walk. He is losing weight and now feels ashamed of his body. He has asked to be given steroids but has been refused.

‘I’ve got to take twelve pain killers a day, just to numb the pain...pain in my whole body...every bone in my body aches’

### *Community*

John actually lives in a South Yorkshire town where he moved after he had been beaten up and stabbed. He had friends locally and he thought they would accept him back but in fact the first day back he got attacked by one of his old friends.

He goes every night to the local gay pub and the bar manager and his staff tell people to 'watch him, he's got AIDS'. The previous week, John was leaving holding hands with a man he had met, and there were audible comments of 'Another AIDS victim'. His friend couldn't handle it and said he didn't want to see John any more.

John often travels to a nearby city where there is a bar where he has been made very welcome and where he feels comfortable, but he doesn't feel able to tell people his status there for fear of losing them. John also is close to someone who lives in the south of England with whom he has had (protected) sex, but when John asked him if he would make a difference if he was HIV positive he said that it most definitely would, 'so I haven't contacted him since'.

### *Moving away*

John cannot afford to move to a different area and would have to make himself homeless in order to be rehoused. One possible option would be to try to get rehoused in Leeds or Blackpool but he would have to get a direct transfer from his local area which is proving difficult to arrange, particularly as HIV is no longer treated as a priority in terms of housing. John is angry because he feels that refugees and asylum seekers are getting priority in terms of housing and services over people that are born in this country. He believes that many asylum seekers are HIV positive and are spreading the virus.

### *Possibilities for the future*

John used to work with children and would like to do so again. He has a dream of going to Africa and working with HIV positive children, and he currently sponsors an HIV positive child in Africa. John describes the work he has done with and for children and as he describes this a real spark comes into his voice. He describes a conversation he had with a child he met on a station platform 'and I made him laugh so much...If I can make somebody happy, I will do, and that's the only thing that's keeping me going'.