

business meeting with my colleagues that afternoon, had to collect myself, control the ache in my throat, and the tears which constantly threatened to stop me in my tracks.

The next week we had a meeting with our solicitors in Sheffield. My brother Iain and Roy's brother-in-law Bill were there as executors of both our wills.

We had updated our wills (they had been written originally under the influence of the naive assumption that I would obviously die first, though there were provisions in the event of a reversal of usual expectations); we signed them and had them witnessed; we signed and had witnessed mutual Enduring Powers of Attorney; we read out and signed a declaration for attachment to our wills.

This called upon anyone who might be concerned in our affairs to treat Roy and me as nearest of next of kin in all respects - financial, inheritance, access to each other or information about each other, and so on - as if we were related by primary blood-ties or were married. We also included a section from the Euthanasia Society's Living Will which requests that, in terminal illness, life should not be fruitlessly prolonged and that pain should be effectively managed even if death is hastened.

Given our unconditional commitment to each other, we had been alarmed at the possibility of others not accepting or respecting our wishes, given that there was no watertight method for formal, legal recognition of our relationship.

We had heard stories of gay partners being refused rights of access to visit in hospital or to medical information; of families removing the body and not involving the partner in the funeral; of houses and belongings being repossessed. We

did not suspect our families were capable of such brutality, but the world was sufficiently unpredictable for us to take every possible precaution.

As it happened, no one at any time ever challenged our rights and wishes, but we had done everything reasonably possible and were relieved and comfortable in the knowledge.

Around this time, Roy went off to Rotherham to visit Vera. He left the house while I was out. I returned to find a pink rose and a sweet note on my desk. It prompted me to write a piece describing the effects of the diagnosis on our lives.

When Roy saw it he was pleased and thought it might help others going through similar experiences. I sent it off to Gay Times and it was published later in the summer. (The text appears on page 253.)

* * * *

17 March Roy's entry: Just sat down after a day in the garden - cleaned out the rabbit and birds, planted several bowls of bulbs which appear to have given up in the house, repotted yukka - hopefully that'll now stand up. Bruce just phoned - he caught same train as me yesterday, so he'll be home anytime.

Thought for today: feeling a lot more (what an ironical term) positive - felt awake and quite with-it - not been dwelling on the subject.

Holidays had always been a particular pleasure for us. Roy always found endless things to amuse him - not least the rockpools and wildlife of seaside and mountain - and we were both capable of that lazy serendipity which makes exploring new places so rich. We'd been to remote

spots in Scotland, on narrow-boats with my brother and his family, to Amsterdam several times, to Jersey, Rome, Barcelona and Seville (southern Spain was just too hot for Roy), and dreamed comfortably of more exotic locations. This time it was to be five days in Amsterdam.

The great city was cool and misty much of the time, but no less bewitching for that, though the temperature was less than comfortable for Roy in a slightly fragile state, and we had some rough patches between us.

* * * *

18 April: We returned here at about 9:30pm last evening after our five nights and five days in Amsterdam. As always it's been a memorable, rich and full holiday in an excellent city where we feel very much at home. Certainly, this morning in London, I feel that I have now arrived in a very foreign country!

Not only have we done and seen a great deal but it's been a holiday with time of great intensity - both of pleasure and on a couple of occasions some tension and conflict - which, happily we recovered from quickly. It was much to do with conflicting moods and priorities, our inner lives and needs being less harmonious and predictable just now. We had to walk round each other very delicately for a time.

Except for one day, Roy was not on form, prone to tiredness, especially as the evening progresses, and has had some stomach discomfort - though we've eaten and drunk hugely.

Without rushing at all, we've done a great deal and seen many sights we've not visited before (particularly Botanical

Gardens and nearby markets; fascinated to see entire bridge-section of major road over a canal (including pavement and street-lights) rise to let ships through).

18 April Roy's entry: Generally good holiday, but couldn't really cope with going out in evenings. I'd had enough through the day, smoky bars and generally not actually wanting to drink made evenings hard work. Day of departure felt lousy - glad to be back at home and in bed.

5 May: It's Saturday, the first day of the bank holiday - and it's beautiful - warm, bright, summery - a gently small breeze - birds singing, everything vigorous and in full growth - and peaceful - inner and outer - it seems for the first time for ages.

Life has been an absolute whirl for weeks - visits to customers round the country, the demands of the office, hectic getting the new business underway - there's so much to do, though the team is really starting to take the weight.

Roy has been in good form - though quickly tired, unpredictable sleep, some sweats, and tummy trouble, drinking less alcohol, eating OK - bearing up. It's difficult to know what to make of it, and I don't know if all this frenzy with the new business is a help or a hindrance for coping with life at home. We've had one or two memorable group meetings at home - especially that Friday when so much booze was consumed it was extraordinary! And we still got a good deal of work done. There's lots of enthusiasm and excitement about.

I wonder what Roy is going to do - perhaps he will get his energy back - is he depressed or ill? - or a bit of both? I wish we knew - it depresses me to see him so sleepy all the time, so vulnerable. I daren't talk about it really as it all makes me want to cry.

Up to this point, we had been dealing with latent, speculative medical problems. Though Roy had clearly not been well, there was nothing particular or identifiable. This was both unnerving and reassuring: unnerving because there was nothing to take hold of and grapple with; reassuring because the absence of illness at least meant things were not immediately grave. This was soon to change.

* * * *

19 May: late: It's two days since Roy was called to the Middlesex after a routine clinic visit. PCP* was diagnosed.

It came as a shock - a gradual, staggering realisation - a terrible fear that he might not come home again. I feel inadequate, uncertain, not knowing how to cope - feeling the awful tension of wanting to be with him and needing to keep hold of house, business, work. I've been disoriented and slightly panicky these last two days (off work Friday) unable to concentrate on customers, restless in the hospital. We've had only short periods together - constant stream of visitors means sociability not intimacy. But the friends are so important - generous, kindly people and so many more on the phone who care about him so much.

When I got back from the hospital on Thursday, Tim held me in his arms while I wept. I've been near to tears

* Starred medical terms like this appear in the glossary on pages 283-286

several times - grieving already for the possible trouble to come.

Roy remains apparently blooming with health - ruddy complexion, cheerful, positive. It's very hard to feel that he's ill at all. Yet this first symptom of the weakness of his defences is terrifying.

After discussion with Roy and his sister, I phoned his mother in Rotherham and told her virtually the whole story - she already suspected - and her reaction was, overall, remarkable - though she said things about how he should never have left home and 'messed about with blokes' and the pain of having children, and so on. But she related things to a wider sphere of reference - we talked about every age having a demon disease - cancer, polio and so on (her sister had had polio) - and how they soon become less terrifying. AIDS will recede in the public consciousness. She talked of his 'going home to be looked after'. I made it clear that this was his home - the place he'd done so much to create and make homely and that he'd be staying here. I said, 'He is not dying.' She was relieved. She was relieved and grateful for the whole communication, I think, though I doubt if she'll sleep much tonight.

I find it difficult to make sense of my feelings - am I denying the reality or over-dramatising it? How serious is the situation really? I've wondered from time to time if I can carry on at all - will the old brain manage all this chaos at once - finishing at the old agency, organising this major exhibition, and a new business, dealing with the staggering change in domestic life - Roy's mum and all - and can I

(should I?) keep all this going and risk neglecting Roy or not dealing, really dealing with the feelings and needs of us both? I think that it's right and best to keep hold of the practical, business world - to keep hold of that - if nothing else to ensure that we have an income. But I mustn't get absorbed in it, escape into it and neglect Roy and us.

And now it looks as though the new premises for the business are going to fall through! But everything else is going brilliantly - exhilaratingly! Wow! What a world of extremes.

After the months of preparation, The Bruce Hugman Partnership Ltd, trading as EQUUS, opened its doors on 1 June.

On our checklist of things to be done while there was time, a trip on Concorde featured as a high priority. So we booked one of those round-trips from Heathrow over the Bay of Biscay.

* * * *

2 June: Ninety minutes on Concorde. It delivered everything we could have wished for.

The previous day Roy had been out and about with Mike - all over town, trains buses here and there - and was, early on, obviously tired as we made our way to Heathrow. It was a lovely bright day, with a blue sky dotted with cotton wool clouds. I was full of anticipation.

Check-in was very friendly and welcoming, then we pottered about - had tea and coffee - and waited for announcements. Eventually made our way to gate 50 where

there were the remains of a simple, but nicely presented buffet - orange juice and rather small sandwiches. Not quite what we had expected, but we held disappointment at bay.

We listened to an interesting talk about supersonic flight, sonic booms, and the unlikelihood of a replacement for Concorde. We were given our plastic model Concordes.

Packed buses out to the tarmac - and there she was, looking fresh and gleaming. What a wonder!

All very relaxed - no one shoving or pushing - and we were quickly seated in the wide, comfortable grey leather seats. From this moment everything lived up to hopes. Great sense of ease and space inside (though tiny in comparison with conventional aircraft) and lots of very friendly staff buzzing about.

First stage - hot flannels to freshen up, then safety information, lots of chat about the plane, wallet in seats with Supersonic Flyer certificate (collected up and signed by Captain) and other bump, then lunch menu given out - huge, eight page stylish article - announcing champagne, fillet beef and lots more - very promising!

Take-off was very fast - pressed deep back into seats, Heathrow tearing past outside - afterburn on for 43 seconds from start, then throttle back and out towards Reading.

Display on bulkhead gave speed and height - climbing at a great rate - eventually to 56,000 feet and Mach 2, with the upper cloud cover below us and the darkness of the outer atmosphere above.

Hardly any sensation on passing through sound barrier - just slight thrust as afterburners were engaged for climb and Mach 2.

Lunch looked - and was - quite excellent - mango/fig/melon starter; fillet beef, chicken and pleasant salad; cheese and biscuits; Concorde chocs in little box - and endless champagne - Taittinger and Lanson coming round actually faster than we could drink it!

The sense of ease, luxury and indulgence as we cruised eleven miles up was terrific - a full realisation of all we could have wished. It lasted long enough - there was no feeling that we needed more - it had been complete. A great experience!

In a euphoric mood, and keen to prolong it, we went to the rather rough bar in Terminal 1 and had a bottle of Mercier. We sat and watched the people and enjoyed a great afterglow.

2 June Concorde (Roy's entry): Big day, felt really knackered early on. Felt better for a glass of champers. Wonderful day. Hospital in evening - had kebab - very nice - cried myself to sleep - no particular reason, didn't get up till 6pm Sunday. Back in bed at 11 and slept well.

Monday met Miss Lodge 4pm at hospital - had cheesecake, ice cream and coffee - cheesecake very nice but stuck our mouths up - had very nice jolly evening at Albert Hall - 'Opera Spectacular'.

Thursday last day on Pentamadine, thank god, getting too laborious. Manda sat with me five hours till I'd seen the doctor - bless her. Felt irritable - bucked up, had chicken etc. for tea.

'Miss Lodge' was a very dear friend with whom Roy individually and the two of us together had a warm and indulgent friendship. She had the most wonderful singing voice

and a great love of opera. At times she could display a theatricality which would not have disgraced Covent Garden. She always dressed elegantly, often with her hair taken tightly back from her forehead with a bun at the back, in the Spanish fashion. Roy loved her poise and energy. He and she would have extravagant evenings of dressing up and vulgarity and high camp - usually in my absence. Though I knew the kinds of things they got up to, it was actually not till long after his death that Sue showed me photos of some of their more exuberant and surprising evenings.

Manda, Roy's niece - his sister's eldest child - was in her teens at this time. She was also a vivid and colourful personality. Enormously overweight, she dressed brightly and sensibly and was a great bundle of good humour and affection. She and Roy were very close. She was always generous, attentive and relaxed. Like Vera - Roy's Mum - she had a broad, ironic, observant sense of humour, and an eye for the ridiculous, deeply rooted in the stoic culture and language of South Yorkshire.

Pentamadine was the drug prescribed to treat and prevent PCP. It was taken through a nebuliser - a gadget consisting of a face mask attached via an ampoule of the drug to an oxygen cylinder. The pressure of the oxygen nebulised the drug which was then inhaled. Roy found it wearisome rather than unpleasant.

* * * *

3 June: So much is happening so quickly it's almost impossible to keep track, to rest, to deal with it all. I have recently wondered if I would survive the astonishing

pressures - especially in relation to sorting out leaving the agency, the million details, negotiations, discussions and so on which the new business demands. Today (Sunday) I feel a bit panic-stricken by the overwhelming demands of the business - particularly the need for me to provide the drive and initiative and inspiration to get things thoroughly moving. There's so much to do - and no phones, fax or computers or printers to do it all with. Things will fall into place, I'm sure, but the requirements are tremendous.

After his first week in hospital, Roy was discharged, to come home and go in for daily treatment. I think he quite enjoyed hospital - so much attention, care, reassurance, to say nothing of the startling social life! Being at home is much more strenuous - making decisions, structuring the day, travelling into town and so on. And there aren't people around to talk, comfort and pass the time.

He seems to have been in good spirits, seems with his great good sense and stability to be living with and dealing with HIV as well as any man could - we've talked a little - I don't think he's haunted by it now as in the early days - he wants to go back to work if possible - though we've talked about the option of medical retirement. Oh, it's so unfair! How can I make up for it, help him make the most of life and energy? I do feel pretty useless.

They gave him the option of stopping treatment for the PCP after fourteen days, but he chose to go on for twenty-one, and he's got another fourteen-day sick note. He was talking about convalescence at the Lighthouse - sounds an excellent idea in due course perhaps - and another of the really good resources available - all reassuring.

He remains calm and good-tempered, though these two last days have left him washed out - snoozing in bed, operating the video with the stick he calls his remote control.

The Lighthouse was one of the remarkable gay-driven organisations which had sprung up in response to AIDS. The most prominent was The Terence Higgins Trust - named after the first gay man known to have died of AIDS-related illness in the UK. All over the world - especially in America and the UK - there was a huge groundswell of concern and activity, a coming-together of commitment and determination in the face of official indifference or sluggishness. Support groups, information networks, convalescent homes, hospices, publications, research activity - often driven by campaigning, heroic gay men sprung up everywhere. Organisations which pre-dated AIDS - like Gay Switchboard in Britain - quickly adapted their services to take account of the new needs for information and help.

The Lighthouse was one of the real beacons in Britain: a place where the sick and the dying could go for love, attention and nursing care. Founded on the values and principles of the hospice movement, it was a place where gay men could be cared for by those who shared and understood the nature of oppression. It was one of the aspects of the larger world which gave us hope and comfort - and a sense of real pride.

By now, Roy had been promoted and carried responsibility, as Security Supervisor, for the wellbeing of the whole range of London Transport's central sites, duties he took very seriously.

* * * *

23 June: Things were so good that he decided to go back to work - I admire his determination because he could easily have chosen to have more time off - hospital offered sick note and support. He is getting very lethargic at home - whole days in bed feeling weary - cheerful but unable to move!

First week back he's really been in good physical form - though feeling some strain - and he completely overdid it on Tuesday (I think) when he zoomed round all his sites, putting in an appearance, getting up to date. He was very tired on Thursday - and feeling very delicate. Friday evening we met up with friends at Gordon's wine bar in Charing Cross and though he felt tired at one point, the two of us left and went for a delicious Indian meal in Clapham. Roy had a glass and a half of wine at the wine bar then a pint of lager with the meal. It was a very agreeable evening especially as we'd not been out together for a meal for a good while.

Roy had a wonderful evening out at the Albert Hall with Sue and has been playing the CD ever since - 'Opera Spectacular'. The Anvil Chorus has become a kind of theme-tune for him. Such ebullience, such vulgarity!

I've missed going to the clinic with him because of several work commitments and also missed the hospital visit yesterday when he went for his pre-AZT blood sample. It sounds as though it was horrible - lots of attempts to get blood and lots of failures - he was obviously at the limits of endurance. Sample taken eventually.

Seems they're going to monitor him carefully to see effects of AZT* - evidently kindly, patient research nurse

explained it all - and gave option not to take part. Roy feels it's a good idea to agree (in spite of prospect of more samples - every fourteen days) and he's pleased to help to find out more - and feels that he may be monitored more closely if he's part of an evaluation.

A Channel 4 Dispatches programme - which we didn't see - has caused great turmoil in the medical world - and for Roy for a few days. He'd almost got to the point of refusing AZT because of it, but there doesn't seem much doubt it was an unbalanced, unreliable study which presented a quite inaccurate picture. Everyone at the hospital was furious about it according to Roy.

Anyway, Wednesday, he got the prescription for AZT and yesterday got a month's supply - 250mg four times a day.

We must try to record accurately how he's been recently to compare with any change. Delicate/queasy stomach from time to time and feeling 'ropey' every two or three days - but seemingly quick recovery next day. Definitely prone to bouts of extreme tiredness even during good days - but sometimes (like yesterday) able to keep going without sleep well into the evening. Tendency to go to bed earlyish - 9 to 10pm - very tired, and seems to be sleeping generally well - some nights frequent waking - but (I think) few sweats recently. I'll leave a space here for his comments.

24 June Roy's entry: You would! Wednesday - saw doctor - she gave me prescription for AZT and told me not to take it until Friday after seeing research nurse - he was a nice chap willing to discuss any questions I asked -

chat for about an hour, then came taking blood - what a performance - me freaking out he couldn't find blood. Eventually other nurse came to do it - my arms were like pin cushions - and felt toothachyish - fancy going through that every fourteen days, but I guess I'll be more closely monitored - also on Wednesday went for Pentamidine only ten minutes. All nurses good but lot of new faces.

Last week had blood taken, had X-ray and blood for oxygen count - everything appears alright but still having coughing fits. Started AZT on Saturday - was quite a step - the only hope but not really wanting to poison my bloodstream - but then it could be said it already is poisoned so we will fight fire with fire.

Spent nearly all weekend gardening and made spaghetti bolognese - sauce very nice.

At this time, AZT was the principal anti-viral drug in use against HIV. Its use was controversial both because of its potential violent and damaging side-effects and because of mixed evidence about its therapeutic effectiveness. Treatment was really still experimental and there were few choices.

24 June: The first day of AZT seems very significant - it's the big chemical gun to add to Roy's psychological armoury at a time when he seems to be in reasonable form. Let's hope it brings back more energy and a greater sense of wellbeing.

What has been strange has been living with this dramatic truth - but both of us carrying on with life - not as if there

was nothing wrong, because we do talk about it, but not letting it get us down or stop us living. Patterns of domestic life have changed - the balance of responsibility between us has shifted a little, I think. With very few exceptions (Friday morning was one) there have been few times of ill-will or disagreement and generally positive feeling and affection.

30 June Roy's entry: Not been a bad week at work but there have been several mornings it's taken a while to get going and been sleeping like a log.

Been on AZT a week now - no serious side-effects but did have a throbbing headache on Tuesday which won't go away in spite of painkillers - don't think this warm muggy weather helps. Going to Flamenco dancing tonight at Sadler's Wells.

1 July Roy's entry: Woke in a strange mood this morning. Feeling quite bright but sombre somehow - don't quite know what to write - feelings and visions keep floating through but I never have a chance to latch onto them - they seem to evade me - I want to get pissed and have a fag and a party but I want to be left alone and get pissed and cry! See I'm choking up now - should I have a drink - it's only - oh, it's later than I thought - it's 11:30 so I may have one - it's now 12:30. Went to feed the birds and ended up cleaning them out, cooking lamb and sorting kitchen out in general. Now on my second glass of wine and feeling a bit better, starting to think about other things, other than the possible bumpy path that may lie ahead. Weather has similar feel today as it had in Scotland - wind strong - whistling up

chimney and letterbox and rattling windows and rain and sunshine. All that's needed now are a few passing joints of venison and it would be complete!

27 August: At home we've hardly had time to stop and notice time flying by. In general Roy has been in very good form - at times, he says, feeling better than ever before - quite wonderful, but then he wondered if AZT were burning him out - but no real sign of that. He's had one or two 'eruptions' (a kind of heat rash and some other oddity) which turned out to be nothing to do with HIV (as far as anyone can tell).

Relations at home have been good (except one night I worked very late at the office and he was cross). We've had some excellent times in London and, especially, on our short hols in Northumberland.

Our determination to make use of our time has been amply fulfilled - we've hardly a free weekend and are booking into November!

There have been times of anxiety - what next? - and Roy has been very shocked by news of the death of two or three from the ward - and of Paul's decline. I haven't seen much of what that has done to his imagination and peace of mind.

He's been much less tired - even through the heat - and on some days has set a pace I've found exhausting. I think it's actually been a very good time for us both - though I've been very tired for much of it with ten or twelve hour days at work, often with things to do on Sundays too. We seem to be doing OK.

16 September: Something of a crisis has been reached: 'I've come to the end of my tether; it's like being in quicksand - clutching at branches; the more you struggle the worse it is.' A grim night. We have to find something active and purposeful.

20 October: Late evening this Saturday, and Roy is in hospital. He has been having sweats again recently, and for some days a persistent, evidently debilitating headache. He has been weary and washed out in the evenings and today looked so helpless on the sofa that I thought he was just giving in. Persuaded him to let me phone the hospital - they invited him in and kept him there for tests and observation. I don't think he's fighting any more.

There have been delightful, good times (even though he's tired quickly) - in Berwick, with friends in Suffolk - but the old spirit's not like it was and he's been so negative, depressive and irritable.

We've had one or two awful days - days of hideous, bitter silence, of relentless, dispiriting aggression; of self-absorption which have excluded and withered me. I have felt his despair? depression? fear? sapping my energy and optimism, draining my vital energies away - and still I've been unable to reach him, to bring him out of it.

Just now his moods - bright or dark - never seem to coincide with mine - when I'm exhausted and drained he's wanting affection and attention; when I'm trying to be bright and attentive he's dark and withdrawn - when he says he wants to hear about what I've been doing I feel he's

bored and I stick to family and house; when I tell him about work and the outside world, he's withdrawn and distant.

There was a lovely phone call out of the blue today from an unknown American who'd read the Gay Times piece - he was so enthusiastic about the content and the quality of the writing - I told Roy - his only reaction was one of anxiety that someone had located me. Why did we write it and send it off? he said. To touch the lives of others. And we did.

There have been good times - lovely moments, some of them even - especially? - after the worst times (that has happened to us before) - moments when the horror and stupidity of having rows collapses with the realisation of how seriously things are going wrong.

It seems as though we had a lovely summer - where did it go? - good, happy, harmonious times when his energy was predictable, when there was optimism.

He picked up in hospital - I think he doesn't know how to keep himself going - he needs to be taken in hand - needs to be in a safe place - being on your own at home doesn't provide that - there's too much time to think, too comfortable a sofa to sink into, too much easy mindless distraction on TV - he so often leaves it on even when I come in, keeping me out, at a distance. And I need nourishment and support too.

He gives too - sometimes I come home and there's a meal prepared. He continues to look after the house and garden - sometimes with great energy - but it's all become terribly, damagingly unpredictable. And he blames me for long hours at work, has been sulky and cross when I come in late. There is so much pressure.

And on him, too, of course. I don't know what to do but to be as steady as I can, with occasional lapses. I don't know what to do.

Recently I have felt anxiety about coming home - fear of what I will find; I still love home, love coming home, but there's doubt and anxiety now - will it be easy, relaxed, affectionate or strained and dispiriting?

I do feel sorry for myself. Tired and strained. Yet I must carry on.

He's finding travel more difficult - car or train - and suffers from frequent stomach pain and discomfort. Some mornings he's so weary he can hardly get out of bed - yet he's not missed a day at work and seems to be keeping his commitments fully under control. That's probably why he has so little spare energy at home.

In other years, I could, perhaps have given up work - we could have spent more good time together - but could we be content without our home, our life without cash to spend? I doubt it. And the penalty for meeting those needs is going out to work. And now, for me, with much more dramatic and demanding responsibility - the business has to be a success, and it can't function without me, not for years.

Once more, he is in the best hands - and anything must be better than the sad state he's been in recently - even with the occasional ups. Let's hope for some good weeks ahead.

11 November 9:15pm: I've just waved him off in the cab back to the hospital, after his thirty hours or so at home.

These are the hard times.

He's so far from well, yet they can find nothing major. Poor Roy, he's been like a laboratory specimen these past weeks - every test known to medical science, endless blood samples (how he hates needles) - how brave he has been as he's been punctured and prodded and invaded.

I've just broken off writing to phone the hospital - talked to the sister who described him as a 'beautiful' patient - and arranged to talk to the consultant tomorrow - perhaps he can help us out of this awful uncertainty.

Not knowing - not knowing what's wrong; not knowing how long it will last; not knowing if he'll get better; not knowing if he'll be his old, energetic, jovial self again; not knowing if he'll always be a patient at home now.

I'm becoming depressed, as he is, at this uncertain future, this painful present.

The quality of medical care we found, and the astonishing quality of the people at the clinic and in the ward amazed us. All our fantasies about hostile sisters were banished from the very beginning.

We learnt what a radical effect the admission of AIDS patients had had upon ward culture: here were vigorous, articulate, almost exclusively young men who insisted on information, choice, collaboration. They wanted to know what lay behind treatment options, what the risks and benefits were; they were not willing to wake up graciously at absurd hours to have their breakfast and their temperatures taken; they were not willing to submit to whatever the Great God Consultant said was good for them. They were determined to make their own informed choices.

All this, of course, should have been par for the course - for any patient, with any illness, in any ward. But it wasn't, and sadly still isn't the case.

What we found were doctors and nurses who deeply and completely accepted their patients as partners in the therapeutic experiment. In those days, of course, it was even more of an experiment than it is now, and those we knew had the realism and humility to acknowledge that there was very little certainty in anything they did. They were learning as they went along and we were grateful that we were included in the process. What we had to say and what we experienced were part of the advancement of science. It made us feel valuable beyond our ordinary value as human beings, which itself was so conspicuously recognised.

The use of 'we' is entirely accurate. While Roy was the patient, there was no time at which that identity superseded his individual rights or human dignity, and no time at which it was not acknowledged that his identity, needs and wishes arose also essentially from our partnership. So, at any time at all, and particularly at crucial times, I was treated as his equal in terms of access to information, participation in decisions, assertion of what we wanted. They understood what we had yet to learn: Roy's morale and wellbeing, and even his health to a real extent, were dependent on the strength and health of our relationship, and on the welfare of both of us individually.

There was, in many respects, a sense of normality about the ward. Perhaps I should say extraordinary normality, because it was a place of humour, kindness, informality, idiosyncrasy, devotion and creativity, where the medicine felt subsidiary to the human relations. Any occasion for celebration and decoration

was seized upon: all the usual festive occasions - Christmas, Easter, birthdays and so on - but also Beaujolais Nouveau Day, Guy Fawkes' night, the annual ward party and much more. There was a sense of vigour and life and optimism about the place. People died on the ward, but they died in an embrace of rare and genuine love.

* * * *

17 November (written on the train en route home from Newcastle): Roy has been in hospital just four weeks now. For three and a half weeks it was tests - day after day - blood tests, bone marrow, lumbar puncture, liver biopsy - such an assault on his frail, feverish body. They found nothing which could explain the fever, sweats, lethargy. White cells had fallen seriously so AZT was stopped - within a week white cells recovered. They decided to give antibiotics in the hope that whatever it was causing the problems would be knocked out. First day and a half of antibiotics (hefty doses intravenously) he was very sluggish and high - third day woke up feeling better; fourth (today) tired - but fevers and sweats have stopped - but he is breathless just moving his position in bed.

Yesterday I had the day off and spent a few hours with him - bathed him, sat, talked - there was really no pressure on time and it was very agreeable. I had been feeling so much pressure, so many things to do, so much dashing around.

This journey - a packed Saturday afternoon train - is a nightmare - I feel hemmed in, restricted, stressed. Wish I'd taken the Weekend First option - open spaces, decent seats - but couldn't smoke.

Our hope and objective at the moment is that he will be well for Christmas and that we can have a few days of peace and quiet together at home.

He fears the prospect of further illness and going through all this horror again.

I really don't know how to survive the pressures of work and visiting, Christmas cards and presents, washing - just keeping going. I leave the house 6:30am - return 9ish after work and hospital, if I'm lucky. It's wearing me down!

But what of his poor body? Can it survive this radical assault both from the virus and the treatment (which isn't at present nearly as radical as it might be)?

He's eaten hardly anything for three weeks (had a bite or two of a burger today and a milkshake) - will he start losing weight? Friends have been very good.

He is so far from being himself.

18 November: I have just returned home from two days' work in Newcastle - and a visit to the hospital where I went straight from the train. Our talk to the consultant lifted the deepest strands of the depression - at least we were coming to the end of 'testing' - but they did not have any idea what was wrong (except very low white cells - hence AZT stopped last week, and low haemoglobin). They were going to start broad spectrum antibiotics in the hope they'd blast whatever the bug was.

They've been pouring the stuff into his veins for three days now and he's no better. The sweats have stopped (except late last night when painkillers provoked a real torrent and his temperature plummeted - they used a foil

heat-conservation blanket they were so alarmed). But he's so weary and now (again) depressed.

Had a chat with night staff nurse tonight - such wisdom and strength and concern (he's been wonderful to Roy over this period) - he thought Roy needed to cry - so much bottled up; he thought there was no more I could do than continue to love him; he offered the ward's camp bed for me to stay overnight in Roy's room. I decided to go home.

I thanked him for his care and affection - expressed again our confidence in the team - their affection, their commitment.

(They had Beaujolais Nouveau and peanuts rattling round on a medical trolley on the ward the other day - they don't miss any opportunity to bring life and entertainment to the place!)

I realise I'd been feeling insecure financially recently - what happens if I'm ill? - can we keep the house on? The business is a risk - there's no comfortable safety net beneath us - we've no wealth behind us - only our deaths will make us rich!

I don't know where we're going.

Tonight we talked of having a quiet Christmas here at home together - that would be wonderful - I hope it's something Roy can pin his hopes on and work towards - he seems so helpless, vulnerable there in his bed - nothing to occupy his mind except his illness.

He had a few bites of a hamburger tonight - but very slight signs of a revival of interest in food.

15 December: He has been home for two weeks now and the improvement in his health and energy has been astonishing. Only three weeks ago in hospital, just walking down the ward was a trial - bathing an agonising, anxious business. Now he's going shopping, pottering about the house - at this minute cooking bacon and egg and fried bread!

We lived on a kind of roller-coaster of highs and lows in health and emotion: from one day to the next it was impossible to anticipate how well Roy would be and where on the spectrum of apparently near-death to exuberant energy we would find his poor body. While our emotions were largely tied to the immediate state of his health each hour and each day, there were also other quite different currents sweeping through us with their own unpredictable and powerful rhythms. These rose from the very deepest aspects of our being, associated with life and death, meaning and purpose of life, the moral emptiness of the universe and all those dark, unknowable fears which live on the edge of existence, and rise up in the wake of crisis.

While the dark times were as dark as anything I ever expect to experience, the bright times were exquisite just because they were at the polar opposite to the previous despair. We had never espoused the middle path, but we had never imagined that such extremities were available either side of it.

Christmas was one of the blissful periods of health, peace and quiet time together. With just the two of us on Christmas Day, we mounted the whole show - stockings, opening presents in bed; full-scale dinner with elaborate

table-setting, candles, silver, fine linen; goose and trimmings - the whole shebang. And the house, as always when Roy was in charge, was festooned with Christmas lights - dozens of sets round every doorway, along every picture rail, round every picture and three or four on the enormous tree - weighed down with his usual dozens and dozens of colourful glass balls. The team was back in action!

* * * *

6 January 1991: The general improvement in his health has continued and he returned to work at the beginning of the month. It does not seem to have been too difficult, though he's tired at the end of the day. He's anxious about the possible implications of his employer finding out about his illness.

I'm not very clear how he's feeling at the deeper levels - he says things have been entirely changed for him - at times he clearly (and reasonably!) feels sorry for himself; at others seems happy simply to carry on 'as normal'.

We had a long talk the other night when he said, amongst other things, that he was 'happy with his lot' - meaning, I think, with our home, our life, how we spend our time, the sense we're managing to make of the inevitable.

We talked about the financial implications of his stopping work. I felt that we could manage tolerably well - especially if the business prospers and my salary increases substantially at the year end. Things will be tighter, but we have been throwing money around fairly liberally!

Since restarting AZT he's been feeling better, though there have been some night sweats and headaches. The indigestion (or whatever) recurs occasionally but doesn't seem too serious. He's still moving about quite slowly and finds stairs a problem at work and home.

With the exception of one incident, we had an almost perfect Christmas break. I had the full ten days off. For the first six days we really did more or less exactly what we pleased - sleeping late, eating, shopping, snoozing, having friends round for drinks, but largely having the time just to ourselves. It was very affectionate and harmonious - a very happy time indeed. Christmas lunch with our free range goose was excellent and it was wonderful just being able to please ourselves.

The only cloud over Christmas - and it was a pretty dark one - was the phone call from his sister on Christmas morning which knocked Roy for six and sent me into a fury of indignation - which I vented fully on the phone to her later in the day. She rang to accuse Roy of selfish disregard for his Mum on the one day in the year when families should stick together. She was in a dark and vicious mood. Roy came back from the phone depressed and dispirited. I brooded on this nasty intrusion for several days and was in no frame of mind to go north and see her and the rest of Roy's family as we had planned.

The trip to Roy's Mum in Rotherham was fine - no nasties or problems - lots of good food, fairly relaxed time, a shopping trip to Meadowhall. Normal - if cool - relations resumed with his sister and no references to the Christmas outrage.

Good time at my parents where we were treated to lots of grub and drink - warmly welcomed. It was great to see my brother and sister-in-law and the two very attractive, civilised nephews.

Before Christmas we went to the ward party which was a remarkable event - the room packed with staff and current and ex-patients all on a serious extravagant binge. There was cabaret - wonderfully tacky and camp with one of the male nurses in a frock and wig and others being very amusing. The whole experience was weird - those excellent nurses letting their hair down - those who had played such a vital part in the health of the party-goers (many of them very ill) and who had given affection and hope so generously.

We presented the ward with a four foot cuddly bear in hat and scarf which remained in the day-room for months afterwards.

The Christmas phone call caused me real fury and turmoil. It touched all kinds of old conflicts and pains. While I had had a very secure and pretty privileged childhood, I had rarely been happy at home. Certainly as I entered puberty and felt the power of my sexuality assert itself, I was deeply uneasy and unsettled. I was equally irritated by my seemingly obsessive mother and apparently passive, diffident father.

Once I went away to University and started work, I found it increasingly difficult to spend more than a few hours at home without becoming irritable and depressed. Leaving home and setting up my own independent existence became something of a crusade including, of course,

resisting the usual duty calls of family life such as going home for Christmas.

'Home' was to be where one's life was centred. It had the extra dimension that, as a gay man, I could not establish the kind of home that most people would take seriously: could there be a home without a wife and children? Well, yes, there could and I was determined to demonstrate how.

Breaking those ties, offending against the constant external and internal iteration of filial and family obligations is a major challenge. In time I achieved what I wanted: where I lived was the centre of my existence with all the depth and weight of 'home'. This meant spending Christmas there with those I chose and who chose me - among my 'pseudo-family' as it was satirically described by one of the witches of the century.

I had achieved this transition before I met Roy. After his initial doubts about leaving Rotherham (which were actually more about declaring his sexuality than leaving), we built two homes together which were absolutely all I could have dreamed of - and which he felt the power of as much as I. But these things are not achieved without struggle against the overwhelming values of so-called normal family life and against the sometimes stentorian claims of those who feel side-lined or neglected - or those who represent such claims through their own frustration and disappointment.

Even Vera, for all her wisdom and strength, found it difficult to comprehend that the home in which Roy would want to be looked after would not be hers. It was as if she saw our years together as a kind of transient interlude which would end with a return to real life.