

indeed may be able to spend only very short periods at home ever again. I cannot imagine life without him. All this has a kind of illusory quality - it's impossible to reconcile the reality of death with his continuing living body even though it is suffering and weak.

Friends have, as in the past, been wonderful - Nicky has been going in each day, an especial comfort to me as there was a risk on Wednesday that I wouldn't get to see him in the evening at all; Terry has been wonderfully supportive and thoughtful, bringing endless bunches of fragrant Casablanca lilies which Roy and I love - he brought me home from the hospital last evening and we sat and had a very brief nightcap and a chat; Peter and Geraldine to whom I spoke for the first time tonight since we returned were touchingly concerned and made the wonderfully practical and helpful offer of doing the shopping for me at the weekend when they went to Sainsbury's and delivering it here. (The great struggle at the moment is simply keeping the practical arrangements of life going and giving myself the odd few minutes each day simply to look at the post, to sit down, to read the paper, to think about what needs to be done to keep the house in order); Cathy has been in to see him; Sue went in earlier in the week and I think gave him a great boost - she seems so ebullient and strong and purposeful now - there was a phone call later in the evening from her, and she struck me as enormously strong and determined, not only for herself but for Roy too. Eric and Audrey and Mary on the phone have been immensely warm, supportive and generous, offering, like so many, to do anything they can to help.

I spoke to Vera tonight and presented the latest news fairly squarely and coolly, without being over gloomy or providing false hopes. She is hoping to come down with Amanda on Monday and stay overnight to see Roy on two days. I was initially rather taken aback by the proposal to stay overnight but made it clear that that was fine (others have rights, too!)

I haven't cried a lot, but I get very near to it as I sit by Roy's bed holding his hand, as he sleeps, looking so helpless and with so little to look forward to. He is still there, he is still holding on to himself, his courage, his spirit, his cheerfulness, his thoughtfulness. I hope he does not lose those great qualities for his own sake and ours.

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It's the afternoon of Sunday 1st September and Roy has been home now for about 24 hours. He arrived Saturday midday looking very pale and frail, carrying his new bright yellow sharps box. Both of us felt that being in hospital was not doing him good - certainly psychologically. The medical team had no objection to his returning home for the weekend (indeed were keen that he should), though the drugs regime was going to be much more complicated and demanding than before. We sat in the garden for a while, then he had to dash to the loo and didn't make it in time. He was annoyed and upset by the accident. I simply set about cleaning up and helping him out of his clothes. Strange how all one's squeamishness absolutely disappears in such circumstances - the main problem was not being properly equipped with adequate cloths, mops and other equipment.

After a short while he decided to have a shower and I helped him with that and he then chose the brilliant, extravagant, Mary Quant shorts and T-shirt I brought him from Heathrow some months ago. I was much moved that while he was feeling so wretched he was dressing so splendidly. He looked lovely, but the contrast between his weak, pale body and the joyful tropical clothes was hard to endure. (On another occasion when he was looking and feeling miserable he chose the Walk for Life T-shirt (an AIDS charity item) which left me pregnant with tears.)

He had another very close shave a short while later, but managed to save his clothes. I mopped up the loo.

After a while he came in to rest in the front room and snoozed on and off for the next few hours.

Later on in the evening Peter and Geraldine arrived with the great Sainsbury's shop that they had done for us, and we sat around chatting about this and that, the holiday and other things, a conversation to which Roy contributed a little but drifted away every so often.

When Peter and Geraldine arrived, Anne Louise, the community care team registrar also came, renewing the syringe pump and giving him an injection of the trial drug through the Hickman line.

After Peter and Geraldine had gone we sat around in the front room for a time, I cooked myself some supper, we watched a bit of television, though Roy dozed through most of it. It took us a long time to get moving to go to bed and once there we were both very restless and I went off to the spare bed after a couple of hours.

During the night I heard Roy up several times being sick and in the morning it was clear he had slept very little and had had a miserable night.

Anne Louise came again around 10 o'clock and gave him some Hyoscine* which for the rest of the day has made Roy almost comatose, muttering now and then, I suspect hallucinating a little, occasionally shocked when he opens his eyes and finds me sitting next to him. I have to remember that the current state is probably the effect of the drugs, but it is enormously distressing - he's almost incoherent, has a very shaky voice, his coordination is doubtful and all I can hope is that somewhere inside him he is pleased to be home. I really don't know what to do and am feeling at a very loose end, comforting myself with talking to the tape recorder and busying myself with washing and other domestic chores.

After talking to an old friend from the north on Thursday or Friday, and discovering that he had tried to take his life a couple of weeks ago, and that he was obviously in a very bad way, I suggested that he come and stay, something that he had said he had wanted as he was looking for 'a sanctuary'.

He is coming about 6 o'clock tonight, more or less the time when Roy will be going back to hospital. I have no idea if this is a good idea, whether it is going to be a comfort or a burden, but I think the prospect of somebody being around during this time will actually be quite a help although I doubt if our friend will be his usual cheerful self. Amanda and Vera are coming to stay

tomorrow for Monday night as well but I am afraid most of the niceties of hospitality may well go by the board on this occasion, though they must be made welcome.

All this stress is not helped by the fact that I am very worried about the business at the moment. July was a bad month with a loss, August I think will be not much better and we really will have to start thinking about major cutbacks, possibly even losses of jobs. I just hope that some decent piece of work comes through very rapidly, or that we manage to generate a substantial amount of income quickly. At the moment I don't feel that anyone is being particularly inventive or resourceful in our sales effort, and I am sure I do not have the energy and imagination and get up and go that is necessary to keep things moving. We have certainly got to act very soon if we are to prevent a serious situation developing.

The business, EQUUS, was just over one year old. There were six staff, a first-year turnover of about £400,000, and shareholders who had put in over £200,000 to get the business going. Even after one year there were only two of us who were significant earners. The pressure to deliver results was huge. Around half of our turnover came from one client (our major shareholder) but that was far from enough to pay the wages and bills on its own. The Company was founded on my reputation and it was I who had to deliver. Apart from the exceptional step of having a whole month off for the world trip, I don't believe any one of my clients (among those I hadn't told) knew there was anything amiss. The business - marketing and training consultancy - involved the delivery of training sessions; the planning and implementing of

marketing campaigns; the research, writing and production of a variety of publications. People paid us for our energy and creativity, so we couldn't afford to be performing at less than 100%.

Though a major leitmotif of my professional life and training message was "The show must go on" whatever might be happening backstage, there's certainly a level at which everything does get a bit mixed up: when, for example, endings in one aspect of life prompt pessimistic and destructive feelings and reactions in a quite different aspect. It was quite a complicated act of will to express and enact a bright and expanding future for the business while, at home, almost every emotional resource was devoted to adjusting to progressive decline and ultimate death.

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It's the evening of Sunday 8 September and it's now about two hours since Peter and Geraldine drove Roy back to the hospital.

Having just listened to the last couple of sentences of the previous entry, I need to add something of a corrective: it turns out that sales in August were rather better than I had feared, though still far from adequate, and what I think was probably a rather gloomy feeling at the time of the last writing has moved on a little to greater optimism and hope. It's nevertheless the case that we still have an enormous amount to achieve in terms of sales and have got to improve our performance and profitability dramatically.

For me the last week has been much better than previously: I think I have now fully recovered from the

anti-climax of returning to the UK after our trip; I have begun to come to terms with the inescapable realities of Roy's health; have begun to get back into my stride at work and have already taken a number of initiatives and had some excellent ideas.

For most of the week back in hospital Roy has been very dopey and hallucinating a good deal from the exotic cocktail of drugs they're giving him. On one occasion when I was sitting by his bed holding his hand, he was tugging violently at it; when he opened his eyes said that he had been trying to draw some curtains and thought my hand was one of them; on another occasion, which he has repeated to a number of people with amusement, Nicky and I were sitting with him when he was drinking a glass of milk and he found himself putting two fingers in the glass, evidently having thought that it was a jar of pickled onions and trying to get an onion out. The week's been full of peculiarities of that kind, including his talking to people who weren't there, thinking people who were there were actually someone else and so on. It's been quite distressing from the point of view of having very little opportunity of coherent communication, though he has been very relaxed and available during his lucid moments - which can end at a second's notice with his eyes rolling upwards and his eyelids closing. It's been odd from the point of view that in some senses he really hasn't been there and much of the time I've spent with him has been in silence, either just holding his hand or on one very agreeable occasion, dozing on the bed with him, his head on my shoulder. Denise, one of the nurses, told us that she

came in for some reason or other, while we were asleep but didn't like to disturb us because, 'We looked like two cherubs!'

He came home yesterday, Saturday, and sat in the front room most of the afternoon and evening, sleeping most of the time, drinking a good deal, eating a little raspberry jelly and ice cream, which he managed to keep down for some time, then went to bed around half past nine or so and seemed to have a quite peaceful night with only a couple of interruptions to go to the loo.

Today, Sunday, seems to have been a very peaceful and refreshing day for him which he spent in bed, sleeping most of the while, coming round every so often to have a drink, to talk to me, to take or make phone calls, but all in a very relaxed way. He himself said that it had been very refreshing to be away from the interruptions and disturbance of the ward - another indication of the perhaps negative effects which being in hospital can have, along with the physical atrophy which sets in through lack of exercise.

At this moment I really don't know how ill he is. I found myself saying in my head on one or two occasions as I sat with him, 'he's dying', and yet I have really no idea. I don't know how a body can continue to survive without eating for so very long and the staff at the hospital seem very reluctant to give him anything substantial which would really sustain him. He is now on intravenous fluids virtually twenty-four hours a day and in addition to the ordinary saline, they are giving him a potassium and saline drip, alternating with a saline, potassium and glucose drip. On Friday they gave him three units of 400 millilitres of blood

as his haemoglobin had dropped. That should provide some degree of nourishment and refreshment for the system.

This evening he actually did seem much more chirpy, though he is still vomiting up even the glasses of water he's drinking while the diarrhoea seems to have been controlled to some extent - though there are still urgent and quite frequent calls.

Our friends continue to be wonderful:, phoning up, calling, visiting, offering practical help. Peter and Geraldine again suggested that they might come and take Roy back to the hospital. Originally I had intended to go back with him, but took the opportunity of a few hours tonight to get myself together. There's the phone again.

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It's the evening of Sunday 15 September and Roy has just returned to hospital and phoned up to say that he was back. We've been using his Taxicard regularly with one company who seem to be enormously efficient - arrive on time, pleasant drivers, modern, smart vehicles - altogether very well organised. With the £7.75 contribution made by the Taxicard the journey usually costs about £6.50 or so each way.

(We have had some awful journeys, though: having to stop the taxi every few minutes for Roy to throw the door open and be sick in the gutter. He, especially, hates anything which is messy or public. I find it quite hard too.)

Last week saw Roy's condition improving relatively dramatically: after having the blood the Friday before last

weekend, the restful weekend at home, and then being on virtually 24 hour tpn drip (total parenteral nutrition) and the various kinds of adjustments they are making to the drug regime. By Wednesday, Thursday, Friday he was really almost back to his normal self, bright, alert, sleeping very little during the day with energy back in his voice and eyes.

This weekend at home, he has been very tired and washed out, though yesterday lunchtime he had some soup and cheese and wasn't sick until late in the evening when he said he fancied pancakes with lemon and sugar but was sick after two or three mouthfuls of the first one. He slept well and this morning fancied a soft boiled egg and 'dippy' soldiers which he ate and enjoyed. (I'm so happy that he actually wants things and I can get them for him.)

We went through the quite elaborate drug regime this morning - one intravenous direct into the Hickman line; one which had to be made up with a bag of saline and taken over an hour or so; followed by a third and a flush of Hephlok.

Because he's been fairly weary, we haven't had much conversation, though we slept together on the bed yesterday and snoozed this afternoon on the sofa.

All week he'd been saying that he fancied a proper roast Sunday lunch, and had asked me to get some beef or lamb. I got a leg of lamb and did that today with Yorkshire pudding and potatoes and whatnot but come the time he had no stomach for it, and I stuffed myself quietly in the kitchen with a glass of wine. He had a morsel or two of lamb later. I actually found myself not caring in the least

about the effort involved in any of these things - the pancakes last night or the lamb today - my overriding interest is in providing him with anything that he feels he has the slightest chance of eating.

This evening as he sat snoozing on the sofa, he looked so pale and fragile - his eyes really are sunken now, and his face really looks gaunt - I thought again with horror that he would look like that when he was dead. It's so difficult to know what the prospects are, whether his body will ever start functioning properly on its own again or whether he'll be totally dependent on the food and drugs which are being pumped into him in such huge quantities. There was the realisation this weekend that without the virtually 100% support of intravenous feeding and total care he could probably not carry on at all.

We've talked about the weekends, and are hoping that he'll manage to get home for as many as possible and we've talked too of his coming home for good - though I have no idea whether that is a reasonable possibility; whether he will be able to manage on his own while I'm out at work.

We had another member of the community care team come round last night, in fact twice because the ward had not sent all the drugs that were necessary. She was absolutely splendid, committed, interested, concerned to make sure that she and the team provided everything that Roy wanted for his comfort and to fulfil the things he wanted to achieve. Really very impressive, and another element of the service we've been given which has greatly impressed us and for which we are very grateful.

I hover between depression and anxiety about him and from time to time the guilty feeling that I wish it was all over. But he is still well enough to take some pleasure in coming home and to look forward to events in the future. While there's hope of him having some good days we must carry on with confidence and optimism though I feel his resources are so weak I can't really imagine what's going to happen.

I've sat down with a glass of whisky tonight but I'm surprised and pleased how little I've taken to drink to get through.

I still really do not know what it is like for him - he still seems to have such spirit on his good days and there seems to be no sign of despair, anger, frustration and no expression of suffering. He is remarkable.

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Soon after that we negotiated his coming home for slightly longer and soon mastered the drugs regime and the new techniques required.

In fact, it was all coming together rather easily, and I popped home at lunchtimes to see to the midday routines.

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During the last couple of weeks back in hospital Roy has been in a much better state with the nausea and diarrhoea much more satisfactorily controlled, though he has been very dopey and slept a large percentage of each day. He's had quite a few visitors, including Eric who popped in on a London day as did Jeremy. Both weeks I have had to

spend two days in Newcastle, and Nicky has visited in my absence.

Today, Ann phoned up asking if Vera could come down next weekend with Lily and Cyril. Both Roy and I, quite independently, came to the conclusion that we wanted our weekends left quiet and peaceful and while he phoned Ann and told her this, I wrote to Lily and Cyril on Vera's behalf telling them about Roy's illness and also to Vera, enclosing a copy of the letter, indicating our thoughts about weekend visits. Roy said, 'We are not pawns in a game,' and we decided that we had to stay in control and not simply give way to every wish expressed from Yorkshire - or anywhere else for that matter. He remains so quietly strong!

We seem to be making some progress with sorting out his employment issues and have now written to his manager explaining the situation, without being explicit, and are awaiting a response from him in relation to the retirement pension, lump sum or whatever arrangements they are willing to make.

We have applied for mobility and attendance allowances, and those look as though they are going through with the necessity of having an examination by a doctor for the mobility allowance once Roy is at home.

At present we are hoping that he may be home next weekend and then permanently as things this weekend really have worked very well, smoothly and simply and Roy has clearly had great pleasure in being here.

Palliative medicine is doing its work, though at the moment it's at the cost of Roy's lucidity and alertness,

though he has many good periods during the day though prone to falling asleep quite unexpectedly. We seem, strangely and inexplicably, to have passed all the main pain and grief barriers, simply taking things as they come day by day, and enjoying what simple pleasures we can - sitting quietly holding hands on the sofa or snoozing in front of some unstimulating television programme.

For me, the world is shrinking to home with him, his hospital bed, and, of course, business. Beyond that very little has any strong or compelling reality in spite of being in the midst of a great, throbbing capital city.

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It's midnight on Sunday 6 October. Roy came home on Thursday evening permanently, a prospect which, I think, had lightened both our moods during the preceding days. I felt a huge sense of relief that we were going to return to as near normal as we could and that the physical burden of hospital visiting would be stopped.

It's been great having him around, comforting, peaceful, a return to some sort of companionship, conversation and a more natural rhythm of communication.

But he is not happy. Out of hospital, and with the distractions of hospital routine out of the way, he is painfully aware of his incapacity, his weakness, the fact that he never feels in good form even after a sound night's sleep.

Today he said he really did not want to go on feeling as he does now and asked if I had had any conversations with the doctors about how long he had left.

He can do none of the things that used to give us so much pleasure - eating a meal with a bottle of wine here or out in town, having a night out at the theatre, even (as he said) having a pint of beer in a pub. At present he is not strong enough to go out of the house to the shops or for a walk on the common; he really hardly has the energy to stay awake in front of a television programme - there's nothing to look forward to, nothing that is full of pleasure.

We agreed that I would phone the on-call community care team member and raise the question of quality of life: they could then consider the option of starting him on steroids* as they had suggested. He was in no doubt that quality was what mattered and he had no interest in lingering on helpless and weak.

He has been depressed, too, by the apparent complications and difficulties of the medical regime, anxious about how he is to cope when I am not here, even the quite simple routines which we managed to go through without thinking on the world trip are now a source of anxiety and take him a great length of time. His deteriorating sight is such that he has difficulty in placing a needle accurately in an ampoule or in the line, and from time to time he does not have the strength to undo the bung or disconnect the drips. (I've had difficulty with some of them.) Some of the anxieties seemed to lift when I said that the great majority of the routines I could do and on occasions when I was going to be away we could make sure that a nurse or one of the community care team came in to help. But those are trivial issues beside the one big one.

So death has been on both our minds today, and as I sit here while he sleeps upstairs I think of it too and wonder how I shall cope. I find myself preparing for it in a way which accepts its inevitability yet I am horrified by the risk of resignation to it. It seems tragic that so much human effort, so much medical resource can do so little to affect or reverse the irresistible progress of disease. Yet, I suppose, what we have now, a degree of stability and comfort, is so much better than a month ago with the constant state of distress and emergency. Yet it's no life, and though there's the tiny chance of a period of remission, the present quality is probably of little value to him, though his continuing existence matters so much to me.

He has eaten a little this weekend - we had soft poached eggs on toast for lunch, and as far as I'm aware he has not been sick, which is great!

While this private tragedy is overwhelming our lives, while we plan to get as simply and comfortably through each day as we can, for me it has heightened an awareness of the millions of tragedies of a similar kind which are happening all the time: those many millions for whom famine and disease are inevitable facts of life with no resources, no comfort, no medicine even to alleviate pain. We are just two people.

We've had the good fortune to have around us the most extraordinary team of nurses and doctors and even today, talking to Anne Louise on the phone there is a degree of commitment, concern and energy which is really remarkable - a commitment to making sure that such time as Roy has left should be as satisfactory as possible in

his terms. That's all been remarkable, because in the midst of this, officiousness or indifference would have made it all unbearable.

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Saturday 2nd November: I think it must be about a month since I have put anything on paper but memories of that period are so overwhelmed by the events of the last couple of days that it is almost a blank to me.

On Friday 25 October a nurse from the ward phoned us to let us know that Keith had died in St Mary's the previous night. (Keith was the other member of the 'Ganciclovir Gang' who used to sit with Roy on the ward talking and giggling as they took their chemo-therapy.) I went back in and told Roy and cried helplessly - I think as much for us as for Keith and Bill, simply overcome by the unstoppable progress of the disease and its shocking, inevitable end.

It was not, I think, until a week later when Bill phoned Roy at home to tell him about the funeral taking place the following day that Roy gave vent to his feelings of sadness and loss. He phoned me at work in tears after talking to Bill who had said affectionate things about Roy's friendship with Keith. I was all for coming home to be with him but he said that was not necessary (he simply wanted to talk with me; he wanted me to get on with my work); though I so much wanted to be with him. I was shaken by the reality of Keith's funeral and by Roy's untypically overt distress and tears.

The next day we arranged a cab to collect Roy from home and to pick me up from work to go on to the

Lighthouse where the service was being held. It was an immensely tearful occasion with many of us crying unashamedly through the service, throats and hearts aching. To be with Roy at such an occasion, frail, ill as he was, struck deep.

The priest was a dead loss, mournful, unemotional, monotonous and I felt the conventional Christian things he had to say were empty, insulting rubbish, which he did not deliver as if even he believed. They did not speak to us, our condition, our beliefs; he did not comfort us, indeed he offended me with his confidence that for Keith the best things were yet to come - an afterlife of rich opportunities and all that. Weren't we searching our souls for ways of making *this* life worthwhile? Weren't we fighting with every resources we had to snatch happiness and pleasure out of darkness and pessimism *now*?

It was what Keith had wanted, but for me it was hollow and unsatisfying, and for Roy, too, I think. Oh for a ceremony to touch the mountainous grief there was in that room - for Keith, for his lover, for the family, for his friends, and for the gay men and their sick and dying friends! Tragic, useless, hurtful, trivial.

Today, Saturday, has been a horrific day. Roy's syringe driver failed to function properly during the night and he's had a day of hideous diarrhoea and emergencies.

We talked early in the morning about his funeral, and made notes of some of the music that he wanted. He said that he wished it had been he who had died and not Keith. He is feeling agitated and unwell, probably, we later realise, the result of withdrawal from the

diamorphine which had not been going through the syringe. But that, with the emotional trauma of Keith's death and the funeral, along with the suddenly assertive symptoms today, certainly made him feel that he did not want to go on. He wondered whether we could make the trip to Paris that we'd planned, and suggested cancelling it or selling the tickets. I resisted this and said we should wait and see and that we would get through this bad patch.

It became evident during the day that the malfunction of the syringe driver was probably in the line so we could not put it right. We called the community care team and Vicky came out in the evening to change the line. She, like the rest of the team, was quite splendid, sensitive, thoughtful, attentive and after changing the line gave Roy a strong injection of morphine and an anti-sickness drug which after an hour or so sent him into a deep sleep.

She then spent about an hour and a half with me, wonderfully sensing that I desperately needed to talk today and we went through all the tough stuff.

Roy was not going to die suddenly, she reassured me, and he would probably not die while I was away. We talked a lot about 'moving the goalposts' (her phrase) looking to much shorter term goals, shorter even than the three weeks to our proposed Paris trip. We talked of the tension I feel between my wish to be with Roy most of the time and the requirement, understood by both of us, that I should be at work and attending to the business. She offered the service of their team of volunteers to stay overnight with Roy when I was away if that comforted

me, suggesting that whether or not Roy felt it was necessary it may be something he should agree to for my sake. She said that should there be any kind of emergency when I was away from London they would let me know and there would be time for me to get back. Though she comforted me with the observation based on the team's experience that Roy would not die when I was away, she said that people do tend to die when they want to. They, as the team, were also committed to letting people die where they wanted to. I told her that Roy and I were in no doubt that that was to be at home.

We talked a lot about quality of life: Roy clearly feels that the present quality is not sufficient and at the current level he'd rather not go on. Vicky and I agreed that resolving that was a joint task: they should try and lift the physical quality of his life a little while I should attend to providing more short term goals and stimulus to make the days immediately ahead more attractive.

He's had such an awful day today - feeling grotty, erupting bowels, three lots of washing. For my needs, I want him to live; but for his, I know that the life he has is not right for him, does not allow him to be himself, does not satisfy him and the prospects of serious improvement are tiny. I have to learn to let go. While he must know that for my happiness his life remains so precious, I have to recognise too that for him, suffering as he is, that may not be enough. Is certainly not enough.

Jackie came today and took the remaining tropical fish from Roy's tank which is now dark and empty. Roy came

down for a few moments while she was here but looked weak and distressed and went almost straight back to bed.

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25th January: It's now a considerable time since I have committed any thoughts to paper. This is a reflection of the two or three months of pressure at work, unremitting activity and anxiety at home and the passing of such hours or days where there have been periods of freedom, largely sleeping or vacantly watching the TV or video.

Following the appalling crisis of November things for Roy did begin to settle down and with the introduction of steroids the symptoms, particularly of vomiting, were almost completely controlled. They did have the disturbing effect, however, of giving his face a swollen, bloated look.

Up to Christmas, there was a period of really extraordinary stability though I think it was evident that he was becoming more and more radically weary and spending more and more time in bed, usually remaining asleep until midday or later, getting up for a couple of hours, snoozing, perhaps on the sofa, and then being at least partly awake during the evenings when I was at home.

The decision to take the steroids was a significant one, and it was one which was precipitated by Roy's clear choice to have what quality he could during the time remaining. This was something we had talked about with the medical team at the Middlesex and the community care team many months before when we were contemplating leaving hospital and managing the illness at home. The medical

team had made it clear to us in the early autumn that we should not expect a very great length of time, and in November in the gentlest, most tentative way, it was indicated again that we should not be deceived by the apparent improvement and stability, and should certainly prepare ourselves for, perhaps, a matter of mere weeks, probably four or five at best.

I can't remember if that precise period was discussed with Roy, but he and I certainly had conversations in which we acknowledged the likely shortness of time, and we prepared ourselves in several ways.

We spent some time with Terry, talking about the funeral arrangements, and the music Roy would like to have. He had some time alone with Terry, and then I joined them and we talked over all the details. We were conscious of the uncanny nature of our conversation, but carried it through with calm, if emotional care and then went on to talk of other things.

Roy was keen also that he should see his mum and she came down with the family. At the time of their visit the drug routines were particularly complex and time-consuming: there was hardly an hour of the day when there weren't tablets to take, drips to be attached or removed, injections into the Hickman line, filling or adjusting the syringe driver. During the time I wasn't cooking or administering drugs, I was in the 'pharmacy' upstairs preparing equipment or mixing the complex cocktails. His Mum was shocked at the state of his health and realised that his physical care was beyond her, however much she might long to have him 'home'.

Roy and I had talked about the business of death and I had said how anxious I was that he might die when I was away and that I hoped he would hold on. The nurses on the ward, like Vicky, had said that most people are able to choose the time and place of their death, and that given the will they will die when and where they want. Roy said that for him it would be on the sofa with his head in my lap, just as we have spent so many evenings in the past few weeks.

For me, the urgent requirement was to do my utmost to spend more time at home and I discussed it with the team at work who were enormously supportive of a potential plan to have say, Tuesday afternoons and Fridays at home, when I could work. Even though Roy may not be awake, it pleases him to have me around. I have done my best since then to shift my working day earlier so I get home earlier to spend what time I can here. The tension of this need is appalling, because the business requires my attention and from time to time I need to go away. I haven't managed to take any significant hours off, though.

We solved this particular problem in relation to my need to go to Newcastle for three or four days by hiring a car and Roy coming with me and our staying in Alnwick.

This expedition and our original plan to go to a large hotel in Whitley Bay where I had stayed frequently before and spent a good deal of money - including the first anniversary dinner for the business - prompted one of the most upsetting responses to our circumstances we experienced. I wrote to the hotel mentioning that I was being accompanied by a convalescent friend who would want

to spend a good deal of his time in the hotel and asking, for example, what time it would be necessary to vacate the room each day for cleaning. The first response to this was a phone call from the wife of the proprietor asking some rather curious and direct questions about Roy's illness and claiming that it was necessary for her to know these things on the grounds of environmental health regulations. I gave very little away but told her that my companion was no risk to anyone and that it was simply a matter of having a change of air and some rest.

Very shortly after this, a single sentence fax was sent through to my office simply saying that the hotel was unable to accept the booking for my convalescing friend. The receptionist then phoned home, where I was, to explain that the fax had gone to work and to report the manager's decision. Having already received the fax at home by this time, I was in a state of purple fury about it, and the poor receptionist got the brunt of my anger and disgust - though I did make it clear that I was not addressing it to her but to the establishment. The incident profoundly upset me and I was contemplating all kinds of revenge on the hotel, which, in the event I have not had the time or energy to pursue. However, they remain on my priority list of those beyond forgiveness, and none of us has been near the place since. What was going on?

Our expedition to Alnwick and the business went really quite well. One evening we had dinner with Darren and Ian (members of the EQUUS team) and Ian's partner, Joanne, at the hotel and the following one with Tony

Kennan (my major client, and, as representative of the major shareholder, fellow director) and his wife Maire.

Ian had been a members of Roy's team at London Transport and he and Roy had become great friends. Roy brought him home to dinner one evening (long before he was ill) and he struck me as a very bright, energetic young man whose talents were under-utilised at LT. I recruited him for my then company (the one that eventually went into liquidation). Much later he became one of the founding shareholders of EQUUS, and ran our Newcastle office.

Some time after that first dinner he told me how nervous he had been about spending an evening with 'the MD'- someone as impressive as rumour suggested I must be. Ian has since shown himself more than able to cope with people of any degree of impressiveness.

When he first worked for me, the Company was (amongst much else) running a Murder Mystery evening on a riverboat on the Thames for a client. Ian and Roy were togged up as our two representatives of the forces of law and order - and both looked pretty stunning in their uniforms amongst the murder victims, swag-carrying villains and drunken party-goers. They'd both done a real security job for us at a major open-air show in the north-east and were, in any circumstance, brilliant at turning their hands to anything that was needed.

Ian was just one of the many excellent people from all walks of life whom Roy met and enjoyed and brought into my life, to its great and continuing enrichment.

Tony Kennan is a long-time client, supporter, friend and companion for me. While we spent relatively little real social

time together, we have been involved in so many projects and were in such constant communication that we came to know and value each other intimately. He was one of a small group of long-established clients who knew all about our domestic situation and were as much at ease with it as with their own.

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Throughout this period, Roy has remained extraordinarily calm, affectionate and sociable with only occasional, short periods of depression - his cheerfulness, affection, continuing gratitude and good spirits are an astonishing testament to his courage and emotional resources. He quite amazes me and all those who see him.

From the beginning, he has been able to put up with the discomforts and indignities of illness with a kind of calm acceptance which remains astonishing.

There was one particular treat during this period.

We were both great fans of the comedienne Victoria Wood, watching her TV shows, going to her live performances and buying her videos. Her sense of humour particularly tickled Roy, and was very similar to his own. She gave us a lot of pleasure.

On the spur of the moment, when things weren't looking too good, I wrote to her telling her about Roy's condition and about how much he enjoyed her shows, asking if she felt she could possibly pop in to see him. In a phone call the next day from her office, her willingness to visit was confirmed and a date was fixed.

All I told Roy a day or two before was that something important was happening on Friday and that he needed to be well. I told the medical team what was happening, that the drugs regime needed to be planned to ensure he was feeling good that day, and that they were not to call during the afternoon.

An hour or two before she was due to arrive, I told Roy who was coming and he clearly thought I was pulling his leg.

At the appointed time she arrived, much to Roy's astonishment and delight, and she spent an hour or so with us in comfortable, relaxing chat.

Roy's pleasure and incredulity were all I could have hoped for, and we were both thrilled and grateful that such a star could find time for us. Her visit said much about her quality. It was a touch of magic in dark times.

Our Christmas turned out to be a delight - all that we could ever have hoped for. Although working on Christmas Eve to the middle of the day, come Christmas Day the holiday mood took over and we slept until late, woke for a cup of tea and opening the presents, then back to sleep before a late afternoon Christmas dinner of goose and trimmings, all done in the comprehensively extravagant style of the household.

Roy had bought me the most wonderful range of exotic and lovely presents - bow-tie and necktie from Liberty, two pretty shaded candle-lamps and other lovely things - brilliant, wonderful presents which left me incredulous at his thoughtfulness and touched me deeply. How he got them or who bought them I don't know - it was just as if Father Christmas had visited.

On Christmas Day and Boxing Day we lazed about, watched television and videos way into the night, luxuriating in the freedom to do just as we pleased without external demands of any kind.

Our trip to Rotherham to Roy's mum in a hire-car the day after Boxing day went smoothly, though virtually from the moment we arrived till the moment we left, a day early, a succession of relatives and friends trooped through the door demanding attention and keen to see Roy. It was all far too much, too exhausting and we left earlier than we had expected longing for the peace and freedom of home.

Two and a half lovely, relaxed days over New Year again, though I was beginning to suffer some agitation in anticipation of the training project in the East Midlands which started at 9 o'clock on the first day back at work, Thursday 2 January.

While we had the hire-car, we accepted an invitation from Peter and Geraldine to go to their home in north London for afternoon tea, which was a delightful resumption of a more normal kind of life and a very pleasant occasion.

Since the new year, Iain and Jenny and the boys came for a Sunday afternoon tea which was, again, delightful, not least because they stayed just for three hours and, understanding our situation, did not impose themselves. (We are both very fond of the nephews and have had some excellent times with them - including the canal-boat week.) The following weekend Kevin and Liz from Doncaster came for Saturday evening and Sunday morning.

On the Saturday Roy and I had been into Balham to have his eye tested in the hope that some corrective lens

could be provided to help him read a little more satisfactorily. The young optometrist was incredulous at the sight of Roy's devastated retina. We came home from that, he went to bed and in the evening he indicated that he would be happy to go out for a meal with Kevin and Liz so we went to the local wine bar, had a lot of wine and good food and returned home pretty merry. Shortly after returning home, Roy was sick. I think was as a result of the unusual exertions of the day and his body simply not being used to so much activity.

In the last week, we have had some anxious times with the reoccurrence of the diarrhoea and a continuing feeling of nausea with some vomiting.

The vomiting has been going on for some time now and the team have been trying to modify the medication to restore the balance after what had become a time of constipation, possibly prompting the vomiting. The balance tipped the other way and things looked as though they were beginning to get out of hand again but after a few days coming and going, alterations to the drugs, introduction of some new ones and so on, today, Saturday, we appear to be reasonably stable although he was sick once this morning.

About three weeks ago he developed a very unpleasant, infected rash in the middle of his pubic hair. A course of antibiotics seems to have reduced the infection and anti-fungal drugs have cleared up the rash considerably, though it is still far from healed. During the treatment of this, it seemed as though he had developed a small patch of KS (Kaposi's Sarcoma• - a typical cancer associated with

AIDS) in the same area which, though the doctors indicated was a matter of only slight concern or likely danger, is a fairly unnerving and worrying development - a further sign of the body's lack of resistance to attack, I think.

Apart from the constant state of anxiety about Roy's fundamental medical condition as well as the more superficial aspect of his daily comfort, the management of AIDS at home is immensely stressful. There have been times when the medical routines were enormously complicated and time-consuming, but even though they are now much simpler, they impose demands which have to be met irrespective of one's mood, energy or inclination. At the moment, the routine in the morning is the relatively simple one of disconnecting the overnight Hartmann's drip and attaching a bung to the line. In the evening, the driver syringe has to be made up (there have been times when this has involved eleven separate ampoules although it is now rather less), the potassium drip has to be made up and the Ganciclovir connected. Recently too, the rash has had to be bathed and dried.

Occasional episodes of vomiting or diarrhoea require psychological and practical response and there is a host of other simple, everyday demands which need to be met because, increasingly, he does not have the energy or motivation to attend to them. During the day there may be various communications to the medical team or information or instructions from them. Evenings and weekends we may be reporting on some slight change in circumstances to the medical team via the air call, discussing action with them, or there may be the fortnightly drugs list to write and deliver. (I