

have a spreadsheet stock-list with about thirty items on it which I update with current requirements and drop into the GP's surgery on my way to work every two weeks.) Then the drugs and equipment to collect that evening - though we are fortunate to have the most wonderful pharmacist at the end of the road who has taken to delivering the large boxes of items we require. (I was always surprised to find myself walking home with enough diamorphine to put the entire local population on cloud 9!)

On some of the occasions when I have been able to get home early, the district nurses or the community care team member has been here and, again, that requires time and attention which fills the hours which might otherwise be free and relaxed. I am happy to do anything that will make him comfortable and will contribute to controlling the illness, but it is an unremitting and draining pressure. There are times when I wonder how I can continue to keep everything going.

There was one very strange period of a few weeks where I, certainly, was in a state of balance after we had 'cleared the decks' between us emotionally and prepared ourselves for death. Then the event for which we had prepared ourselves so thoroughly did not happen. Day to day it seemed almost as if we were simply waiting, that there was nothing else for us to do, nothing to keep us going, nothing to plan for. That period came to an end when we discussed it together and with the doctors, looking at the extraordinary question of 'permission to let go'. It's evident that in spite of such low energy, such little to look forward to, so little to hope for, Roy is not willing to give up, to let go yet.

Now, I think we regard each day as a gift which has to be taken as it comes; we have, to some extent, started thinking a little more about the short-term future - actively planning visits from friends, thinking of things we might do - even, today, talking about the possibility of booking our free TWA tickets to the West Coast of America - though both of us know, and Roy said, that the chances of our doing it are minimal. In respect of other things, our planning is much more low key but its resumption has taken us out of what was a rather gloomy waiting-room.

In spite of everything, perhaps because of it all, we are having times of the most extraordinary intimacy and affection without any hint of tension or difficulty between us. My desperate need is for occasional times to myself, quiet hours, away from the distraction of external events and demands and to know the ways in which I can make Roy more comfortable and comforted. He is really so undemanding personally, so accepting of the necessities of my life that he appears not to feel there is anything else which it is possible to give him or that he needs. I dearly hope that is the case, I do ask him, and I do not know if there is more we can do.

We were moved by Freddie Mercury's death. We watched the tribute programmes to him and our Queen videos feeling an extraordinary degree of identification and closeness with him, and admiration and pleasure in what he achieved.

We have also been watching the videotapes of the world trip and that has been lovely - not I think in any

nostalgic, regretful way, but as an affirmation, a confirmation, a reminder of what we achieved against such odds.

It's the evening of Sunday 2nd February 1992. We've just come to the end of a disturbing and disturbed fortnight. The conclusion is probably that Roy has gone through a significant stage of deterioration and we must adjust ourselves once more to shortening perspectives.

It's disturbing how rapidly things move out of memory, developments which one would imagine would be etched in fire in one's brain. Time has been passing at such a speed, days have been so full, here and at work they are quickly dissolving into a single hazy past.

As things became slightly calmer, after bowels and stomach were a little more settled, we planned to go to Yorkshire, calling in at Roy's Mum's, where he would stay when I went on to Newcastle for one night. The journey to Rotherham was pleasant, companionable and without problems and I set off early on the Monday morning for the north. During that day he had several episodes of diarrhoea and was, I think, sick once and was evidently feeling generally well below the levels of the previous weeks. I returned on the Tuesday evening, very late having driven through thick and freezing fog. He was welcoming and kindly as always, but evidently frail and under the weather.

The next day, Wednesday, we set out at about midday in quite bad fog, though nothing like the previous evening, and happily it cleared once we were out of Yorkshire.

I had already spoken to the community care team asking that we should have a 'ward round' as I felt that we needed to look at the whole situation and all the symptoms together and decide on a proper plan and adjust our expectations to the whole reality.

The journey home was easy and trouble-free and it was great to be back at home together with time for one of our quiet, companionable evenings dozing on the sofa in front of the TV.

On the Thursday, Anne-Louise paid a flying visit to look at the rash, his sinusitis and the numbness of the left half of his face which had recently begun. It was thought this might be associated with the sinusitis, though that hardly seemed to explain it.

On Friday afternoon I arrived home for the meeting with Anne-Louise and Vicky and it became evident that the sinusitis was actually much more serious than we had realised - a thick infection of the sinuses is difficult to clear, and with its proximity to the nervous system, major blood vessels and the brain is potentially very serious indeed. They prescribed a heavy arsenal of antibiotics to attack this, along with nasal drops to try and clear some of the passages.

With Anne-Louise and Vicky being air called and on and off the phone, we had several conversations in various combinations of the four of us, and it became clear that we probably had to accept a significant deterioration in Roy's condition with the particular threat of the sinus infection possibly spreading much more radically.

With the arrival of more tablets taking the daily total up to thirty or so, we organised to substitute some of them for injections to try and reduce the load.

When we had been reorganising the drug regime on the previous occasion and the number of daily tablets had risen to an intolerable level, several of them had been dropped, including the one thought possibly to have some effect on the cryptosporidium. Roy had said earlier this week that he had a feeling that his condition had deteriorated since that had stopped, so they listened and reinstated it. Being eight large tablets a day it considerably increased the burden of tablet-taking.

Within minutes of the medical team leaving on Friday, a potential new employee arrived for his interview and Roy retired to the back room to sleep. Having consumed a couple of bottles of wine and a brandy between the two of us once the formalities were over, I was pretty well-oiled by the time the now appointed candidate left. Roy was quite upset that on a day when such radical issues had been foremost in our minds, I could 'go off and get pissed'. I was in no state to justify my behaviour or respond sensitively to his distress, let the matter drop, and quickly it passed.

This was something profound and lasting I was taught by Roy - express feelings, get them out of the way and move on - lengthy analytical conversations (as were my habit) just kept things on the boil. The latter part of the evening, and the weekend resumed normal, quiet, friendly relations with no subsequent evidence of the first, tiny friction we have had between us for months. I have not

yet addressed the bigger issues of Friday afternoon with him but need time to do so - when?

It's nearly one o'clock on Sunday night and we have just been through a lengthy evening routine following the Ganciclovir, four injections, connecting up the Hartmann's solution with the potassium, washing the rash, applying cream, and taking the nose drops. I fear that while the virulence of the rash is declining there is evidence of other unpleasant things happening, including possibly the arrival of more KS.

The sinuses seem to have loosened and eased a little today, and I just hope that he will have at least that relief, and recover some of the sensation in the left hand side of his face.

Tonight we sat and watched together our tape of the most beautiful programme about several American people of all kinds who are HIV positive and facing the crisis with incredible openness, courage, even humour. It was full of glorious things, including splendid statements about the huge strength of the gay community; the generosity and love shown between friends and lovers; the incredible strength and determination of people of all kinds, including a middle-aged married couple, a young newly-married couple and several others all coping with lives so much like our own. Roy watched and dozed and saw some of it.

I was encouraged to watch the tape by Roy's Mum phoning up and saying she had seen it. It had evidently given her some food for thought and comfort - I think realising that what we were going through was just a tiny

part of a global drama, not some isolated, squalid, regrettable, untypical private incident. It was a beautiful programme.

The DIARY

Part IV

March 1992

At this stage, it was just two years since Roy's diagnosis and slightly less since PCP had arrived - the first identified symptomatic illness. His lungs were occasionally troublesome, but they had remained more or less stable with the infection held in check. The other invasions had progressively weakened him as their effects accumulated and accelerated: CMV had led to blindness in his right eye and was eating away at the retina of his left; cryptosporidium in his stomach and gut subverting the whole digestive system with permanent, underlying diarrhoea; infected open sores and small patches of skin cancer in the groin; progressive numbness in the left side of his face where the original infection in the sinuses had taken hold and spread to affect the facial nerves.

These were the things we knew about; what other infections, if any, were working away unnoticed, or what other effects the known infections were having, we didn't know. What we did know was, that in the effort to control the

known infections and to boost his immune system, gallons of vicious chemicals had been poured into his bloodstream, and kilograms of unforgiving tablets had been in and out of his stomach. While there was some evidence of cause and effect in particular treatments and their results - most obvious in the impact of Pentamidine on PCP, in the palliative drugs, the steroids and the magical effect of morphine on chronically uncontrollable bowels - much of the process was uncertain and experimental. We had no idea if the chemo-therapy actually inhibited the progress of CMV in his eyes; massive doses of broad-spectrum antibiotics sometimes had positive effects on suspected, unidentified infections, sometimes not; whether or not AZT influenced the progress of HIV was not apparent (though the unpleasant side-effects were all too clear).

What the medical team were able to do with remarkable skill was symptom-management, sometimes, by their own admission, using wildly unconventional, high-risk methods. With relatively little concern for anything beyond the short to medium term (and in the last months, only the very short-term), they could manipulate the drug regime and target a special day or week (or, early on, as much as a month in the case of the world trip) and provide Roy with a reasonably comfortable, limited period of strength when it was a priority for him.

But they were as surprised as anyone by the constant unpredictability of his physical condition: the repeated, sudden plunges into apparently final decline; the equally rapid revivals to brightness and strength. For these there was no rationale at all: at times it must simply have been remission of the infectious assault; at others Roy's indomitable spirit

and the life force within him. We were to see more of this extraordinary process even in the face of death.

While the good periods were a cause of rejoicing, they could not disguise the gradual ebbing of strength and life from his frail and damaged body. Now, in March 1992, the end was drawing nearer, though it was not at all to be the process we had envisaged - inasfar as we had envisaged anything clearly. It was to be both more complex and more beautiful than we could ever have imagined, and both of us became acquainted with aspects of being which were exceptional and mysterious.

It was also to be a time of chaos and panic and mess. Mystery was the last thing in our minds as we struggled with the all-too physical reality of a body in its last, wretched struggles. But mystery there was, and peace, too, even amidst such disorder.

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1 March Sunday: After preparing ourselves for the worst before Christmas, we've been given more time - much more - than the medical team expected. Much of it has been positive and delightful. Roy has maintained that cheerful, generous spirit through many real trials.

This last weekend, I went very near the edge - inner chaos, sleeplessness for a night, a day of disorientation and low productivity. I think it was all to do with energy and stress - too little of the former, too much of the latter.

At a time when the business has been dodgy - though not in crisis - and we're still not profitable - when there are three redundancies completed or in hand - when there

isn't enough business to see us through to the future - the demands at home, the early mornings, late nights - all with the complex medical routines - have sapped my vital energy. I can manage the public performances perfectly - lectures, training and presentations round the country - but very quickly tire.

There is also the profound, intense problem of endings - as I prepare myself for the most radical ending of my life, it is very hard to live and believe in continuity - especially of the business which is not as healthy as it should be: can I find the drive, optimism, direction for it while I prepare for death? How's that conflict affecting my feeling, thinking, performance in ways I can't recognise?

I had long talk with Rob (palliative care consultant) and Vicky (palliative team community care nurse) the other evening while Roy slept: they offered respite - one day's medical routines carried out by someone else, for example; they offered the liberation of expressing my feeling of weakness. I find it difficult to think of giving up the nursing - in however small a measure - as it's so deeply - automatically - instinctively? - identified with my commitment to Roy. Rob rightly said it's the uncertainty which is debilitating - particularly the uncertainty of how long I have to find the resources to carry on for. The conversation was a relief - it's given me strength and some clarity about where I must go - at work for example. I think I also felt I could carry on a bit longer afterwards.

We also talked about my rage at the district nurse's Christian missionary activities in the sickroom. (One day she had read or sung hymns to him when he was comatose

and I was at work.) Rob and Vicky admitted (to my intellectual astonishment) that their purpose in work was to 'bring about the kingdom of God' - but they acknowledged the vital issue of patients' freedom of choice and that their aims remained private and invisible.

There's a strange paradox - at the point of vulnerability approaching death, people are bound to be susceptible to comforting images and prospects - relatively defenceless; but, also, at that point there is (it has to be admitted) also unique confrontation with issues which may have been exhaustively resolved during health, but which now take on a quite different aspect. I pointed out that part of my objection was to the sectarian approach (naive Christianity) - when there were thousands of faiths or systems of thought and values, any one of which might offer comfort or glimpses of a greater truth. It was not part of my deal with the local health centre that one quaint faith should be introduced into the sickroom. I wrote a furious letter which didn't get sent.

It's been a very tough time - for Roy too as he finds less energy, fewer days when he's feeling relatively well.

But we continue peacefully and companionably to watch TV, videos, snooze together, eat well - and enjoy the prospect and reality of eating (it's still one of the things which brings a brightness to his face - cakes especially!)

He's fed up, as he says, with 'people mauling his groin' - and getting through the cleaning routine three times a day as prescribed is painful and difficult.

6 March: It seems certain that he is dying, and likely that he will go very soon, this weekend, they say. I feel eerily

reconciled, ready. Rob has just left - after another of those extraordinary conversations flying from the potent reality of Roy sleeping above us to the grand issues of life, death, meaning, quality of life and all the rest - and back again. Rob is a philosopher and has the depth and breadth - and empathy - to help throw light on the most abstruse of thoughts and inklings. Emotionally I could never have coped without his wisdom and support; intellectually and spiritually I would never have covered such ground as was possible with him and Vicky.

The time is precious. He is sleeping, deeply sedated. He's woken a few times when I've been to see him - comfortable it seems after the headache of this morning and of yesterday, and the sickness. He wanted nothing - just towels to cover the pillow and over him while he sweated.

He has kept his life, his spirit to the end - AIDS has not diminished that lovely being - though his body has suffered and declined he's remained gentle, affectionate - and - oh dear! grateful. Such greatness of spirit. What a guy.

Detail is so precious - it can never come again - to hold onto what has been so rich - terrible and lovely a period. Between us there has been such harmony, such intimacy, such affection, closeness, that it has been wonderful - not even, but especially those many dozy evenings on the sofa - his hand seeking mine - us both half asleep, still, together.

7 March Saturday: We slept well - me after a couple of sleeping pills, Roy peacefully - with the unnerving, drug-induced breathing pattern Rob predicted - ten to fifteen seconds silence between each exhalation before resuming.

This morning he's been quite peaceful - awake for minutes at a time and pretty coherent - just the edge of confusion about time, day, telephone (does it work?) and so on. We decided we would not tell his Mum about the position, but he wanted to call her and sister and family later on. We agreed we'd see it through here, together, with a few of our friends.

I cried this morning, holding his hand. He said again - as he said so often - 'I don't feel any different' - still aware of all the possibilities of life, knowing he hasn't the strength.

I said he was to let me know of anything at all he wanted - however extravagant - if he wanted to talk to the captain of the QE2, I'd phone him. He replied: 'Just the little miracle man who can replace all the bits.'

He said, 'I don't want to be alone,' and I promised that he wouldn't be. He wanted me with him.

I have to face the working week - how many of the days can I take off? We'll see. Hour by hour. We'll see about tomorrow, Sunday, and then Monday.

It's the strangest time - quiet, peaceful, yet emotionally charged: tears are not far away. He has not cried.

One aspect of all this - unexpected, bizarre - is that the time of death seems dependent, quite substantially, on external factors - the assessment of the medics ('Is it now or soon?') - their clinical reaction to things (withdrawal of antibiotics, abandoning the regime of drugs) - and on me (and them) curiously nudging him towards the final moment - Rob would call it giving Roy 'permission' to go - I have to believe it's helpful - the alternative (perhaps) is

his lingering, deeply sedated - but to what purpose for him? (Life is precious, letting go an anxious and frightening decision - perhaps we need to help, reassure, comfort, even hasten the moment.) Rob suggested that I should say that I really have to go to work on Monday - perhaps it would help Roy to slip away this weekend - to take the hint, to spare me the trouble, I suppose. It's not an easy idea to live with if it's not absolutely right for Roy. Can we ever be sure what is right for him?

Though sleepy and sleeping much, he is still so thoughtful: asking for orange juice this morning he said I was to shower and dress beforehand, it could wait.

(Sue's with him now - he asked her if she'd like a cup of tea. We made one for him. She was telling me about the time he was hooked up to the Ganciclovir drip hung from the chandelier downstairs and still asked if he could get her anything! He has always been - and remains - so beautifully altruistic.)

Slowly, since yesterday (Friday when I worked effectively until 7pm) all affairs outside the house are receding - even work is beyond serious thought at the moment - I ask myself if I want to go on with it at all - it's all been so much devoted to keeping our house and life afloat and finances liquid and free from worry - without Roy I should perhaps be doing something less strenuous! Though, I dare say, I shall be glad of the distraction and the discipline.

He was deeply asleep for hours into the night. I sat with him holding his hand, expecting him to die any moment. What would it be like? Would I recognise the moment, would I know for sure? Eventually I slipped into bed with

him - watching, listening, expecting every breath to be his last. Then I fell a sleep.

Sheer willpower - that's what's kept him going.

8 March Sunday: Well, what a disorienting switch-back of emotions! Today he is bright, lively, chatty, lighthearted - Roy as of old - hardly dopey from drugs - eating and drinking, bright-eyed. It's absolutely knocked me for six after the death-watch by his bed yesterday - it's been a delight, but at the same time - having, yesterday, just about adjusted myself - and at the boundaries of emotional, imaginative energy - I hardly know what to do now. As I write (6pm - he's sleeping after Terry's visit and scrambled egg, toast, milk) I feel that I can hardly face the outside world and its demands at all - I want it all to go away for good. Reading about Anthony Powell in the Sunday paper - a leisurely life with money behind him - I just longed for peace and freedom. I am facing, in full knowledge, what I imagine goes on in the heads of those who have nervous breakdowns - it's all just too much. I feel very close to incompetence, impotence.

The business needs prime energy and leadership - now more than ever I've got to be on the ball, up to the minute - and I just don't feel I can cope with it. I shall have to. There's so much at stake - yet, in my heart of hearts, now, I can't be bothered with it. I wait for a miracle - an order for 20,000 of the books; the huge contract offering immediate pay-off - my fantasy life is actually more of the collapse and liquidation variety - it's so hard to separate home and away - home's perspectives are hours or days -

and inevitable ending - how can I feel and act at work in a perspective of optimistic weeks, months, years?

It's all very hard - and in spite of all the support and help we've got - no one can lift the burden.

10 March: Two more days of comfort, good spirits, much sleep - after Sunday's hours of unexpected sunshine. Sunday and Monday evenings he struggled downstairs and snacked, drank, watched TV (though he can see very little now) and then launched himself back upstairs. On Sunday he agreed that he didn't mind my going to work - he'd prefer to be alone than have strangers in the house. Monday had a comforting blanket bath from nurse Cathy. Terry's lilies blooming and pouring sweet scent into the room.

This evening - Nicky visited - Roy ate a little - tottered (quite competently) to the loo - satisfactory visit followed by strip wash on his own. Back to bed - good humour - moments of abstraction - that smile ever available. In the end he didn't get downstairs - left too late - but he's in good form. Wants his Ganciclovir done tonight. All exhaustingly well!

14 March Saturday: Apparently quite stable up to yesterday - very sleepy, but lucid periods between sleeps. Thursday and Friday evenings he struggled down for a few hours - painfully slowly - taking ages to shift from lying, ages to stand up - waiting for strength and circulation to return to his legs, and then slow progress, holding my arm to the top of the stairs. He came down on his own, with

me just a couple of steps ahead. He was comfortable, propped up on extra cushions on the sofa - ate (fruit salad, Yorkshire biscuits and tea last night) while we watched Victoria Wood and Educating Rita. Back upstairs was a tremendous struggle for him - bent forward, grasping both bannisters, panting once he'd got to the top - but he implicitly refused any substantial assistance. Even turning in bed, getting up on an elbow to have a drink is a huge effort.

Tuesday and Wednesday at home for me were relatively easy - I got a lot of EQUUS things done at home (though energy started to fail in the afternoon) and then there was the awful problem of deciding about Thursday and Friday. The prospect of being 'out there' again and away from him put me into a complete dither - should I/shouldn't I go? Should I/shouldn't I keep the appointment in Manchester? I phoned Ben to cancel Friday - but no reply - then I talked it over with Roy (he didn't get up that evening) and he said I was to go and get on with things. His strength and clarity allowed me to do so. On Thursday I was surprisingly clear-headed and purposeful at work, and the trip to the North West went well - I knew the district nurses would be in twice, and I phoned three times - Roy on each occasion sounding very strong and clear.

Today there seems to have been a change. While we were both still in bed he said he felt sick, and prepared himself two or three times. He wasn't. At about 11 I got up and gave him intravenous dexamethasone and other drugs while he remained apparently asleep. Since then - up to

4pm or so - he's not really woken up - no response to voice, even with eyes open - and no hand pressure in response to mine. Nicky and nurse Cathy came. I couldn't rouse him. Then a few minutes of being awake - remembering nothing of the day so far - wanted cold orange, help with turning over (such a struggle for him) and back to sleep. I sat with him, then fell asleep myself. The appearance is that he is slipping away - but he's fooled us plenty of times before!

Last night, after we'd been watching TV (although having drawn up the syringe for the driver and got the Ganciclovir in the room early in the evening - I completely forgot both until about 11pm) - by the time we started moving (around midnight) I was so tired I wondered how I was going to be able to get through the duties - helping him up, undressing, drawing up syringes, making his hot water bottle - an hour's worth - but eventually it was done. I took a couple of sleeping tablets and slept soundly. (I've taken them three or four out of the last seven nights I think.)

There are awful moments - often quite unexpected: I got back from shopping sometime in the last week - and as I came through the front gate, I felt how it would be returning to an empty house; I hover between wishing it were all over - and absolute delight at his continuing, substantial psychological presence - he has moments - longer periods too - when he's so full of spirit, good humour, so much himself - his smile, his kindness, his (again!) gratitude.

I don't believe he's shown a moment of anger or irritability for weeks - though I think he did tell the district

nurse off yesterday for being too rough and boisterous when she was washing him! We joke about the two of them - old-fashioned bossy boots as they both are! But they're kindly and efficient and well-intentioned.

I've said to one or two friends this week - and it's a powerful feeling - that everything else in the world seems trivial and inconsequential outside this house - outside Roy's room. I've had several moments of euphoric imagining how things would be without the pressure and tension of external demands - a little country retreat, a career as a writer, setting my own pace and goals, having a secure income without all the anxiety and pressure. I thought about resigning from the business - selling up, disappearing. Obviously I've not done anything about it - but I know I don't have the energy - and available optimism - that work needs. I'm doing everything necessary - and (to my amazement) doing much of it very well I think - drawing on that great reservoir of skill, experience, knowledge - the brain functioning (almost on auto-pilot) remarkably when the circumstances and stimuli are right.

As I write now, I wonder about all this scribble - what use will it be - will I ever want to, or have the patience to make anything of it? I'm so much of an improviser in some ways - seat of the pants stuff so often (though often inspired too!) that I may not have the patience to process so many pages.

Writing now is something to do with not wanting to lose any of this - this huge, unique, extraordinary, awful reality - not to lose anything while he still lives and breathes in the room above me, because life is soon to change with such

drama. I do not feel it will be the end of the world - there's even a sense of the likely relief - the opening of horizons - once it's over - I do not feel guilty about that, for I would profoundly prefer it not to happen at all - but my world has shrunk to this tiny, physical compass, to this vast, resonant, gloomy, sad prospect - and I am longing for wider horizons again.

But what I shall do emotionally without him, I simply don't know. Our relationship has been so rewarding, so harmonious, so influential - he has changed me - so many of the ways I react, feel - act (even down to cleaning up in the kitchen when I cook!) - much of it in ways I can only glimpse occasionally. He has such an uncorrupted character in many ways - direct, spontaneous, lacking (I think) the complex, labyrinthine emotional inner life that has been my reality - not that he's not complex, but it's a complexity lived with ease, with simplicity, I think. Our feelings and reactions have become so very close in so many areas over the years - differences resolved happily - quite a contrast to the few conflicts and battles we had early on - rare as they were.

That closeness has borne lovely fruits over the period of his illness, I think - especially recently when I have felt our intimacy without barriers - often without words - intensely. I require nothing from him - what he is and what he gives is wonderfully enough.

He seems at peace, too, I don't feel that there's anything he feels I should be or should be doing more than I am.

In the most heroic vein he has been fighting this plague with all his huge reserves of energy and determination.

When I've mentioned it, he's said words to the effect, 'Well, you've got to!' and his struggle to get out of bed, at cost of such effort, is a daily, extraordinary demonstration of what is huge moral and physical strength.

Today it looks as though even that energy is waning fast.

The peace between us has also, I think, been peaceful reconciliation to reality - he's not reconciled to the act or decision of letting go - he's not willing to die - may never reach that point - but to the fact that he will soon die, we are both reconciled.

I do not know whether I should be sitting by him the entire time, or getting on with things around the house - including this record - but I feel I need to keep doing - though returning to him every thirty or forty minutes. Last weekend showed me the intense, all absorbing cul-de-sac which awaits - and I can't risk going back into that. He knows I'm close by.

The shrinking of horizons, and adaptation to them has been a remarkable process. The community care team have talked a good deal about this with us - the issue of quality. The most dramatic decision was in the autumn when we agreed to the starting of steroids - knowing that the cost might be in terms of less time, but the benefit being better quality. And quality was delivered generously.

There have been several 'moves of the goalposts' to shorter perspectives since then - until now it is just an hour or two a day when he is even conscious and when what he has is no more than absence of gross pain, me and some sense of physical and psychological comfort.

Prior to this stage the daily area of quality was simply getting up when I came home, eating together (and how precious those meals were - usually pretty good stuff, some full roast meals, with Marks and Spencer luxuries of various sorts) - though sometimes he'd eat little or nothing (I hoped he'd eat but didn't mind if he didn't, however elaborate the meal), settling down in front of the TV together and him snoozing most of the time - that was an oasis of quality to which he was quite reconciled. Now, it's so much less, but I think it's been OK.

I suppose I'm obsessed with writing about all this because I feel nothing so intense or important is ever likely to happen again - that it is the single, most vivid and intense experience of my life - that it is valuable, beautiful, terrifying - bringing us - together - in the company of issues and feelings which one can hardly expect ever to imagine.

Also, of course, I feel that in the end, I shall have to - want to - write about it: perhaps out of this tragedy I shall be able to create an inspiring memorial - to Roy, his heroism, our love, for those who are facing the same drama.

It changes one's perspectives, yet again! - on suffering and death - how can we permit people to suffer so much - to visit on others voluntarily the pain and grief we have had imposed on us or to neglect its relief?

I've just been up to look at him. A brief fluttering into consciousness. 'Are you alright?' he asks me. There is nothing he wants. His eyes close. A slight knitting, frowning of the brows - a passing, disturbing image or memory. He does not look absolutely at peace, but he does not look troubled.

16 March Monday: Yesterday was a bad day for me - feeling disoriented, depressed, fragile. I mooched about achieving less than enough (whatever enough might be), dabbled with a piece of pessimistic writing about the human race - but was comforted by the registrar late in the evening who, sensing my trouble, prescribed whisky and sleeping tablets.

Later on, Roy had urgent loo call - panic! - slight accident - bulk OK on the commode - but I feared my handling of him wasn't too effective or gentle. Second alarm at 7am today - made it to the commode, but again, difficult, awkward. He can't be left on his own!

11pm: Tried to work at home today - lots of interruptions, distractions - district nurse in the morning, learning to lift Roy, incontinence equipment, changing sheets. Reassuring volunteer co-ordinator phoned - volunteer Dennis turned up - reassuring, competent too - colleague from work came for meeting - consultant, trainee nurse and district nurse arrived - whirlwind activity - Roy out of bed - on the commode - bed sheets changed - new comfy, medical mattress in place - washed, cleaned - commode emptied and cleaned.

Roy's just said he couldn't believe how many people there'd been and how much going on: 'You standing in the middle of the whirlwind scratchin' your head!' he said to me.

All movement is uncomfortable now - all's fine when he's still - but turning, drinking, all major operations. Very tiring. I thought I'd reached the edge with medical routines

- now all this - and (bliss!) five hours a day to go out to work while volunteer sits in. Oh dear.

And he's had a headache today he didn't mention and I didn't know about.

17 March Tuesday 11:45pm: A frightening day! Late last night I was whacked - had a couple of small whiskies and two sleeping tablets and went to bed. 3am - ouch! - Roy needs underwear, etc., changing. I don't think I was very gentle or kind - I don't really remember - except being panic-stricken about the effect on the next day's work. It took about an hour.

Woken at 6:50 by Roy in same position again. I was in a bad way emotionally - there's something very oppressive about shit - not the substance - but the meaning, the difficulty of the routine (removing nappies, knickers with Roy's weight on half the mess), the slow, risky removal trying to prevent leakage, the evidently upsetting effect on Roy of the physical movement and harassment.

I managed to shower and have some breakfast before colleague from work arrived at about 9am.

Earlier, Roy had said he wanted to phone his mum, sister and niece - he felt the time was getting close.

This is the first time he's been so explicit. I took that as a serious indication of change - of imminent change. We discussed if I was to go out while the volunteer sat in - yes, Roy said. 'You'll hang on for me?' I said. 'Yes,' he said.

I phoned the community care team and reported in. Said I was going out for my five hours to put my world in order and get back here permanently. As the day progressed

that resolve hardened. At work I went through everything - I think very clear-headedly - and left at 2:30pm feeling there weren't any loose ends and that things were in strong capable hands. Irrespective of Roy's condition tomorrow I'm staying at home for as long as it takes now.

I lay on the bed with him for a few hours after I got home - then best part of four hours nursing. One accident - I phoned community care team for advice - just got that cleaned up and new knickers on, when another - much looser and more threatening. Agreed to leave him as he was for a little time in case there was more.

Returned, cut knickers off, re-equipped and settled - almost immediately he thought he was going to go again. Didn't, much to my relief. I was beginning to be very hot and weary. Several sessions of dripping water into his mouth with a toothbrush, then a drink of orange. Got him to sign get well card for his Mum and birthday card for sister. He talked to them both on the phone. One or two odd hallucinations for me: 'Must I get up and go to work?' - plus one or two other secret frights which had no words.

Thank god I'm not going to work - I'm only just keeping myself together - physically even more than emotionally.

Roy seems quite peaceful. I asked him if he felt it was coming close. 'Yes, a feeling.' Was he frightened of anything. 'No.' Good news.

18 March Wednesday-Midnight: This chap is continually incredible. After a day of almost completely unconscious, he's just asked to sit on the edge of the bed for a drink. Lifted up by my newly learnt nurse's hold, he

sat up (initially several empty retches - alarmingly) and then drank one and a half glasses of orange and half a glass of water. (He'd drunk very little from glasses or cups for some time, needing all liquids dripped into his mouth.)

We had the most sustained chat for a long time (intermittent for ten minutes) - about nurses, volunteers, my plans - not going to work - at which he said, 'You're not going to let it jeopardise the business?' - I reassured him. The brain - the generous Roy - is still in there, active and alive.

Then he suggested that they might give him supplementary feeding through the Hickman line - those huge bags with the beeping machine on the drip stand. Well! I asked him if he'd changed his mind from yesterday (about time being short). He said you couldn't tell. (Burst of inner turmoil for me - how much longer?)

It's been a bad day for me - woke up with headache and feeling groggy - didn't improve till after one and a half hour's sleep this afternoon while volunteer sat in and watched Roy.

Volunteer Dennis was splendid this morning - Roy already needed changing when he arrived, then he did the most enormous, forceful pee which soaked right up to his chest in the sheets. Dennis and I between us changed everything - me lifting Roy onto his feet briefly - then all fresh and comfortable. It would not have been possible on my own.

Roy finds one of the district nurses a discomfoting person - she's not gentle he says and doesn't do what he says - he didn't want washing and she washed him!

I've spent much of the (pottering) day looking through all our photos to find a selection of ones of Roy to mount for the funeral. I've also decided it will be a champagne buffet, fifty candles, flowers - an occasion to celebrate his life and courage. At the present rate, however, the plans will be on ice indefinitely! He's so weak and sleepy, yet there's a dynamo at work inside. He knows just what he wants and when he wants time to decide what he wants, and is quite clear. He's also so appreciative - in an ordinary, generous, courteous way - 'Please' every time, or, 'Well done!' or, 'Oh! Well done!' on occasions (a successful and comfortable lift for example). He succumbs willingly to the routines - turning - 'It's time to turn,' I say; 'OK,' he says.

He seems to be almost totally blind in his left eye now as well - says he can't see my face - can't see any difference when the main light's put on. Can just see moving hand directly in front of face. Poor guy. He's not complaining - though last night asked if we couldn't stop the diamorphine, I think so that he could be more alert (he's on half a gram a day (enough to zap an elephant) and it makes him very woozy). Blindness was always what he feared most - yet now he is living with it peacefully. Oh my, what strength; what drama!

Being off work has been a great relief - though I've really not been well enough to enjoy it. There are lots of resources on hand - volunteer overnight, etc. - they're a remarkable bunch.

19 March Thursday: It's 5:30am - an hour and a half after I woke to find Roy with the covers turned down

looking for his glass of drink (at the very passive stage of looking - he had the intention). He then said he needed to go to the loo. Debate about commode or not. Agreed too much trouble - and too risky getting there. Agreed to get on with it. Checked pads etc. Covered him up. He looked very unhappy, 'Very embarrassing,' he said it was - eyes screwed shut, holding my hand. It was a huge, very liquid stool which flooded out round his buttocks and settled like a little lake. I was inwardly appalled. Suggested getting on-call team nurse. Roy said he'd rather we did it. He was very practical and clear. So we set about it slowly and methodically and with his active co-operation - first, staying absolutely still, then moving from side to side, completed the whole operation in about forty minutes or so - powdered, dressed and clean. It was a miracle the bed didn't get soiled.

Then it was time for a drink. Lift, and up onto the edge of the bed (we've got this one sorted now!). Glass of orange and back to sleep for him; tea and diary for me. I feel fine - calm, practical, alert. We've had an amusing and agreeable exchange - matter of fact about immediate requirements, whimsical about a tequila sunrise and special barman for Mr Deakin (he asked for the same one he had last time - who let him 'cling on' while he was drinking). Roy entered the spirit of things beautifully. It's noticeable how quickly he's adapted to loss of sight by using his hands to feel for things and check. He never forgets the syringe-driver or the bowl by his side. Still, in the midst of mess and indignity, calm and warm and kindly.

I do wonder how long this will continue. We must get the medication sorted out - this routine is no fun for

either of us - but the alternative may be masses of diamorphine and much deeper sedation. I don't really want that when he's in such good humour - it would be sad for him not to be able to express it and for me not to enjoy it.

Thursday midnight: this guy is amazing. These snippets - him having just gone blind, knowing he's dying:

BH: I'm just going round the bed.

RD: Just going round the bend?

BH: Oh! I've been there for years.

RD: F T. No comment.

or,

RD: The orange is odd. What kind is it?

BH: Robinson's whole orange.

RD: It's a bit odd.

BH: I'll write to Mr Robinson and tell him his orange is odd.

RD: Cricket's cancelled.

BH: Why's that?

RD: The orange is off.

- all with a cheeky smile on his lips - poor lips that are so dry he has to have paraffin wax on them so that he can get a grip on the straw.

A very busy day for visitors! Registrar, GP, district nurse arrived just after two volunteers had left - slight bedlam!

Medical review suggested putting up diamorphine to 700mg per day (it's been 500 for ten days or so); Buscopan stays at 120mg (up recently from 60, then 100 because of diarrhoea); Nozinan up to 37.5 (last three days or so); and Midazolam 5mg all in syringe driver. Some