

modestly adventurous life; we have not seriously abused or neglected each other; we have had a good time in two excellent homes with many, much-loved friends.

Now we know all that could end soon, we are changing our priorities to some extent: it is less relevant to save for the future now - we should spend and enjoy. We should do some of the things we've always wanted to do. We should make the most of the time, the people, the opportunities. We should do everything we can to stay in our home - if he must be ill, let it be here - and so I must earn to compensate for the possible loss of his wage. We must sort out our practical and financial affairs.

So-we have flown Concorde (ninety minutes of supersonic luxury, champagne all the way); next we may blow our savings on the Orient Express or on a flight round the world; we are spending more time with our friends; we are going to more concerts and plays; we are taking more quiet time together; I have left a modest, stable job and set up my own business; we have had a serious session with our solicitors and executors. Our house is in material order; we are not in retreat.

He still cries himself to sleep from time to time, fearful of the future; is still occasionally angry and resentful; is often weary. I sometimes wake up with tears in my eyes and an ache in my throat, or find myself about to weep on the street or the train. If I let myself, I fear the future horribly: his suffering, my inadequacy, the end, whenever, to come.

Our suffering does not compare with those who have been through to the end, or have lost their loved ones: we still have

each other; he still has the strength to visit his mum in the north, and the spirit to leave me a sweet-smelling pink rose from our garden. If only it could last for ever!

* * * *

In the early days of knowing he was HIV+ (in March this year) we found it worrying and difficult to be out of each other's company for any length of time. For him it was, I think, his shocked sense of sudden weakness and vulnerability - alone, he felt at risk from the demon in his body, and frail in a world which had suddenly delivered such a hostile blow to his hopes. For us both it was a compelling need simply to be together, while my early, and continuing fear was that something dramatic might happen when I was away from him.

I have found it very difficult, without a sense of unreasonable guilt, to continue meeting the demands of my business, and to allow myself to become absorbed in the outside world and its concerns. It's a particularly painful process because I miss his best hours in the day: he's asleep (or at least sleepy) when I leave in the morning, and weary by the time I return in the evening. Yet it obviously has to be done if we are to stay here, comfortably in our home, when he can no longer earn.

After eight weeks or so we had just about come to some kind of terms with HIV on a day to day basis, though he was not in good health and we feared there was definitely something wrong. He continued to work throughout that time, taking his lunch hours for clinic visits, which we made together.

I arrived home one afternoon to find him packing a suitcase: he was to be admitted to hospital for investigation of a patch on his lung which had shown up on the X-ray.

It was devastating news. In dealing originally with the reality of the positive test, one of our strategies had been to reflect that at least the result did not make him ill, and that it could be a long time before illness emerged. That was swept away - he now had PCP, one of the most typical 'opportunistic' infections of a damaged immune system, and we had to accept that he was more vulnerable than we had hoped.

The shock was compensated for, to some extent, by there now being something more definite than the previous general sense of unspecific malaise and anxiety: now there was a focus for concern and a busy team of doctors and nurses, investigating, monitoring, advising and prescribing.

The week in hospital was extraordinary. The staff were remarkable in the quality of care they offered - changing his sheets, for example, two or three times a night after the worst sweats (a quality of care which had the reverse effect on my confidence, of course, in terms of what I felt I could provide for him at home); our friends turned up in their crowds, some of them staying around for hours. Much of the time he was in great form - the bright, affectionate, humorous chap we'd all known and loved over the years - he looked a picture of blooming health.

There were those in the ward who were very ill, and we were both reminded - he especially - of the great variety

of ways in which the body can be invaded and wasted, and of the potentially helpless, lingering last stages. It is that, certainly, which he fears for himself, and I fear for us both.

It is almost uncanny, but I think we have both grieved already a good deal for his death - not accepted it, not resigned ourselves to it - but faced it as a real possibility, together mourned for it and begun to prepare for it. It is the most terrible truth - for him the theft of twenty, thirty, forty years which he (like us all) assumed lay ahead of him - half a lifetime of relationships, holidays, pleasures, adventures; for me, the loss not only of those anticipated years of enjoyment together, but also of my centre, my anchor in an uncertain and lonely world.

Let him have strength and health, but let him not linger helplessly and painfully.

In the early days, amidst the grief and the drama, we were also very businesslike in attending to practical affairs, and we have since been grateful for that foresight.

After a couple of years living together, we had made wills, appointing each other as executors along with his brother-in-law and my brother, and making each other principal beneficiaries of our estates.

Knowing, however, that our relationship had no status in law, and that meddling bureaucrats or unsympathetic medical authorities could stand between us or seek to discount our wishes (all facts and possibilities which make us angry and indignant) we wanted, in view of the new situation, to strengthen our position.

We arranged a meeting with our solicitors and executors. First, we signed slightly revised wills. Second, we read out, and then had signed and witnessed a statement declaring our absolute wishes with regard to our rights over each other. This says, essentially, that all persons and authorities are to regard each of us as nearest next of kin of the other with regard to all practical and financial matters, with regard to hospital visiting and access to medical information, and with regard to funeral arrangements. We also appended a paragraph from the 'Living Will' of the Voluntary Euthanasia Society which asks that life should not be artificially or painfully prolonged.

This declaration probably has no ultimate legal status, but it at least means that our solicitors and families are in no doubt at all about, and have formally (and willingly) consented to our wishes.

Finally, we each signed *Power of Enduring Attorney* for each other. This does have full legal status, and is enforceable in the courts. It empowers each of us to act in law *as if he were the other person* - to sign cheques, make contracts, dispose of property and so on. Within the current state of our unhelpful legal system it is the nearest a gay couple can approach to achieving the rights and benefits of marriage. It is the most absolute act of mutual commitment in legal terms.

To those who have not thought deeply about such matters, or who have not experienced the sheer indifference - brutality even - of families and people in positions of authority in the face of a gay partner or bereaved lover, all

this may seem completely over the top. It is not: when it comes to the crunch our world can still be mean, hostile and cruel. The risks are too great to be left to chance.

So, when he was admitted to hospital, it was one less anxiety to know that we'd been through all the formalities - at the worst I could show an obstructive sister the Power of Attorney and threaten to go to court.

In the event, it was, happily on this occasion, entirely superfluous. Without exception the medics and nurses - several of them ingenuously gay - welcomed me as his lover without reservation. That itself was a healing experience for us both.

Friends and medics all ask if I have been tested. I have not been and have no intention of being as long as I am well. What would the knowledge achieve? It would be reassuring to know that I was negative, but knowing of a positive result would simply double our anxiety and stress at a time when we need all the strength and optimism we can muster. I am much more concerned about infecting him with my summer cold bug than I am about my HIV status: that is no risk to anyone.

Our friends' reactions have been a source of strength and comfort. Telling our parents seemed, in comparison, to be a thorny, dangerous path to walk.

He had never told his widowed mother that he was gay, and we were now confronted with delivering a double blow to her peace of mind. She had been anxious for some time about his health - worrying on the phone and in her letters - and we suspected that she might - in her worst moments - have lighted on the truth.

His admission to hospital meant we had to face the issue: she would be deeply hurt and offended to learn that she had been excluded, and we had no business to deprive her of her mother's rights.

On the second night of his admission, when she already knew that he was in hospital, I phoned her, with Roy's and the family's agreement, to tell her what I could, going as far as her reaction allowed.

I had carefully thought through what I should say and how she would react, and was ready to be frank.

We were on the phone for an hour. It was clearly appalling for her, but she showed the same strength and courage which has been so clear in his own reaction to the crisis.

'Just tell me it's not AIDS,' she said at one point, and I thought how a mother's heart misses nothing. 'He should never have left home,' she said; 'What's he doing messing about with blokes?' 'He should come home to be looked after.' So we talked slowly through it all - that staying at home or leaving would have made no difference; that it was not some isolated encounter, but that men had always been his choice; that his home, which he had built with such love, was here, with me.

And she heard it all, absorbed it, and sadly but toughly accepted it. Remarkable people, some mothers.

Since then she has stayed with us for a weekend with daughter and son-in-law, and she has been cheerful and supportive and undemanding.

So, now he is with her in the north for two or three days - and she won't ask him to clip the hedge or move the

furniture as she used to. They will have time together for the first time since she has known the full story, and it may be an emotional visit. They have always been close in all but that one matter.

In his absence, I write this. It is partly my way of processing and understanding what is happening to us - even, perhaps, of keeping control of it through the discipline of analysis and the movement of the pen across the page. But there is also a wish to share our experience with others - to make a contribution to understanding and coping with this nightmare which haunts all our lives, and can pounce on any one of us at any time.

We've done nothing remarkable, suffered nothing exceptional. We've found our love sustaining us in the crisis and we're going to live actively and happily while we have time. We are proud of what we are and of what we have achieved together, and we have not wasted our opportunities.

And the pink rose he left for me gives off its fragrance, reminding me how much I love him.

Pieces Published in *Gay Times*

The Best of Times is Now

January 1993

He died at home, in his sleep, just after five in the morning that Friday, three weeks ago. His breathing slowed, thinned and evaporated effortlessly. I held his hand and said goodbye. I did not cry then.

The previous ten days had been rough for both of us: for him as he became increasingly helpless - recently blind, progressively debilitated, unable to swallow more than a few drops of liquid at a time, subject to the tyranny of congested chest, nauseous stomach, and unpredictable bowels; for me, working and nursing, beyond all the boundaries of physical and emotional resources I had ever crossed before.

Yet though he had suffered so much, it was really only at some point on the last day that the final hair's breadth of quality of life disappeared for him - the point at which I knew, and I'm sure he knew that there could be nothing more to take pleasure in. Only then was he ready, and was I willing, at last to let go.

For two years, knowledge of the prospect of death had had its influence on every aspect of our lives: we had raged

against the implacable reality of HIV, wept, grieved and speculated; we had put our affairs in order - wills, powers of attorney, planned the funeral; but, above all, decided that we were not going to waste a moment of the time or a drop of the energy we had left together.

As an increasing burden of illness undermined his strength and capacities, between long periods in hospital, he continued to work, we flew on Concorde, went to America, continued eating, drinking and spending time with friends whenever possible, and, in our grandest assertion, spent a month travelling round the world in some style (we didn't have the cash for the trip, so we borrowed against the security of his life assurance policies - a transaction which the bank, though willing, actually found more difficult to deal with than we did. We knew what we wanted and got on with it). There was no desperation, simply determination that the time we had left should be rich and memorable.

What mattered for us both was quality of life, not quantity. His choice for a shorter and better life was uncompromising and we were fortunate in having a medical team who understood such things and offered that choice. It's one of the mysteries of such things that in choosing quality we were also granted quantity - far more than anyone expected.

Such clarity about what we wanted in general and in particular - to be up and capable for this day, this visit, this weekend, this event, to be fit and equipped for a month round the world - made the medical team's task that much simpler: their planning - like our own - was directed to

more or less immediate, specific goals: in the early days, they were all external, active events; as time passed, they were less to do with activity and more about achieving a comfortable state of being.

We learnt that quality of life is not necessarily some grand and sumptuous state, and absolutely not about hankering for some vision of what might be: it is about achieving the best that is possible in the present moment. While he was active and relatively well, quality was achieved by exploiting all our available resources - physical, emotional, financial - and doing everything that we could - Concorde, the world trip, and so on, so that we could never reflect regretfully, 'If only...'

As he became weaker, house-bound and eventually bed-ridden so the scope of quality narrowed, adjusted progressively to what was possible, but its richness did not diminish.

What he was able to do, with astonishingly courageous realism was to reconcile himself to each loss of strength, faculty, opportunity and to live fully within the boundaries of what was possible within the present. Two examples illustrate this extraordinary adaptability - the wisdom of which I could only follow with humility.

For the last six months he was - as we both wished - at home. In the early days he would be up and about for a few hours each day while I was out at work and then have an afternoon snooze. He got up when I came in, we ate together and spent the evening talking together, with friends, on the phone or watching TV or videos. Gradually he spent more and more time in bed during the

day, getting up only after I'd been in for an hour or two, and spending just a couple of hours dozing in my lap on the sofa before going back to bed. They were hours of quiet, undemanding, lovely intimacy.

Exploring his perception of the quality of his life, the consultant asked him if his day with this couple of good hours was good enough. In a powerful phrase - all the more so for its being quite untypical in its language - he said, 'It is sufficient'. And he continued to enjoy those couple of hours until he could no longer haul himself up and down the stairs, when the criteria for quality had to be redefined once again.

The other indication of his capacity to hold precious the moment was much later when he was blind and bed-ridden, and when the arena of quality was becoming relatively microscopic. He was eating nothing and drinking very little - that little dripped into his mouth from a syringe. On two nights he woke up wanting a drink. The first time he asked for milk. I brought him half a pint straight from the fridge, and he insisted on sitting up on the edge of the bed. He drank half at one go and said, 'That is so beautiful.'

On the second occasion, after reviewing the range of drinks in the house, he said he'd like an ice cream soda with ice cream in it. He had one, adored it, and promptly asked for another - the evident, immediate pleasure being enriched by childhood memories of similar, exceptional indulgence.

In the midst of raging illness, debility, helplessness, such moments have a kind of glory about them - in spite

of everything he was able to give himself over to intense pleasure.

There was, then, a hair's breadth of quality, which was, at that time for him, no less full and real than drinking champagne on the Orient Express had been the previous year. He could release the Orient Express as a possibility and savour the next focus of quality though it was on an ever-diminishing scale. Only when there was nothing left on the scale did he choose to die.

Quality was not simply delicious drinks in the middle of the night. His ability to adapt to shrinking horizons stemmed from his own heroic strength, but also from much else which fed that strength and allowed it to flourish.

One element was certainly being at home - the home we had created together, on which he had lavished such care, in which we had had such happy times together and with friends.

Wonderful though the loving care had been on the ward, there is something enervating and debilitating about being in hospital. However generous the regime, you are not in charge, cannot call the tune, are not on your own territory. We were both clear we wanted him to be cared for at home - and he wanted, as he said, to die on our sofa with his head in my lap.

That the ward staff and the community care team unreservedly understood and accepted this choice of ours put us back in charge and left us to live freely according to our own rhythms.

We were given that degree of control, too, in full participation in planning the immensely complex,

constantly changing medical and drugs regime. Opting for quality led to the decision, for example, to start on steroids, with all the possible - but to us both, acceptable - risks, and similarly, constantly, in every respect the costs and benefits of one course of action or another were jointly reviewed and action agreed.

The practical realities - endless, complex, demanding as they were - existed within a rich context of relationships: with doctors, nurses, friends, family and between the two of us.

There was no time at which we ever felt any kind of isolation; indeed there was such a constant outpouring of affection and support from professionals and friends alike that we were buoyed up by it in our storm-tossed sea which could otherwise have been so terrifying and threatening.

Between the two of us there was a degree of peace and intimacy which intensified as the months progressed. We had, over the two years of illness, covered so much ground together - said all that we had to say, looked in the face of death, mourned the progressive loss of strength, faculty, our joint future - that we had nothing to do but to be together, to relish each other's simple continuing existence. This, too, was part of his experience of quality.

Towards the end I was struck by the strange beauty of his unreserved dependence, his vulnerable, child-like helplessness, his confidence, faith. His frailty, his decline from such strong, capable, self-assured adulthood broke my heart, but I was moved by the trust which allowed his needs to be so apparent, so available, so readily expressed. What frightened me was fear of my insufficiency to meet them,

to remain patient and kind, and, at times, to keep going at all. He remained concerned about my welfare to the end.

Death had been predicted before - months before - on several occasions. On one such occasion - a Saturday - he had hardly been conscious for three days - I sat with him almost the entire day, holding his hand, preparing myself. In the evening he came round and we talked a little. I asked him if he felt that time was closing in. He asked me if that was what the doctors thought. I said yes and asked him if he was frightened of what lay ahead. No, he said, it was only the process - possible pain - which frightened him. He went back to sleep. I sat and waited, then got into bed beside him, lay listening for a time, and eventually slept for a little while.

Sunday morning, he woke bright and talkative, hungry, humorous, demanding tea and scrambled egg. I was knocked for six, hardly able to respond to positive, chirpy demands from the emotional depth of the death-watch I had been through. He'd done it again! 'Death be not proud!' - he was not going until he was ready - certainly not on the say-so of the doctor - not until the last urge for the smallest pleasure had gone for good - and that was not to be for a further six weeks or so.

We talked together and with the medics about dying, about his needing 'permission' to go, not least from me - with my stubborn, instinctive tendency to hold on, to protect and prolong his precious existence: how could I say 'goodbye' knowing that it might allow him to die?

For him the problem was different: 'What do I have to do?' he asked the consultant in one of their conversations.

‘Look through the brochures and decide where you want to go,’ was the essence of the profoundly wise and helpful response. I don’t know if that’s what he did, but what I know is that he let go when quality went, and that was, not coincidentally, at the time I felt it had gone too.

The day before he died - he was barely conscious - was a day of mess and discomfort and urgent practical demands. Early in the day there were three or four of the medical team in the house, including the registrar who had suggested she would insert a urine catheter (he had not up to that day been incontinent).

I took her aside and said that I felt the last vestige of quality had now gone, and that he would no longer wish to be kept going (the catheter was a powerful symbol of all that he had wanted to avoid - indignity, loss of control especially). I also said how aware I was that such a judgement risked reflecting my own needs rather than his, but even so I felt I knew his mind. I showed her the paragraph from the Euthanasia Society’s *Living Will* which we had both included in our wills (‘If there is no reasonable prospect of my recovery...I request that I be allowed to die...and that I receive whatever quantity of drugs may be required to keep me free from pain or distress even if the moment of death is hastened.’) ‘What do you want me to do?’ she asked. ‘Nothing,’ I replied (quite unable to take responsibility for making a request which, in any case, I knew she could not fulfil), ‘but don’t do anything that will prolong it.’

After two or three hours, everything was in order - after days of coughing, his throat had cleared, the catheter was in,

there was clean bed-linen, he was comfortable and asleep. I felt a great sense of relief - as if some physical and emotional mountain had been climbed, and there was a peaceful, clear view to the horizon.

I now know that we had both let go. And that night he died.

I was much less troubled by the moment of death and by his body than I had imagined. The nurse who was sitting in that night laid him out and went home, leaving me alone in the house. I felt a kind of affectionate familiarity about the body, but its power was only in what it reminded me of and the loss of that made me cry. But it was not in any sense him lying there, it was merely a discarded shell.

So, when they came later to take ‘him’ away - after his Mum and family had arrived to sit by the bed for a while - I did not feel that I was being dispossessed, that he was being taken from me; a potent symbol yes, and the wrench was detaching myself from its meaning not its substance, for he had gone forever in the night, hours before.

We took leave of him at an emotional and extravagant funeral at the London Lighthouse: we had discussed it last autumn with the friend who was to be master of ceremonies on the day, and we knew it was to be a party. ‘A leave-taking and a celebration of his life and courage’ - with music chosen by him, with friends and family sharing their memories of him with tears, much laughter - and an inordinate amount of champagne.

It was a moving and wonderful occasion - with time and opportunity for companionable grief before and after the non-religious ceremony; with those who had had so much

pleasure in his company leaning with their champagne on his coffin as if it were on a bar, talking, reminiscing, laughing, crying.

For me it created such a vivid, rich picture of his thirty-two years that I felt him restored to me in his full vigour - moving the diminished, suffering patient into a less overwhelming perspective, placing it in the context of a whole life, full of energy, humour and pleasure. It was a grand finale which, to my surprise, left me strengthened and comforted, with a sense of fulfilment rather than of bereavement.

I have felt, too, that my burden of grief has been less than I expected: we cried and mourned together a good deal over the last two years - mourned the progressive loss of strength, energy, opportunity; cried as we reconciled ourselves to the fact that the companionable old age we had envisaged would not occur. But we had also been deeply satisfied with - proud of - what we had achieved together over nearly nine years, and especially how in the two years since he had become ill we had done all we could and had left so little unfinished business between us.

So, the house is empty, and I, bereft of the centre and anchor of my life. But he is still here, within me - not in any bizarre psychic sense - but inasmuch as the fruits of living, sharing, learning, growing in the sweetness of intimacy can never be taken away. Being single again is a miserable fact of life in the short term, but I face it with an enduring sense of fulfilment, of pride in what we made together of the hazardous enterprise of being human; and - like him - I face the future with a determination to find

quality, not in reminiscence or nostalgia, not in idle aching for the unattainable, but in the best that is possible now, at this very moment.

EPILOGUE

by

Rob George and Vicky Robinson

We earn our living looking after the incurably ill and dying, in what is called Specialist Palliative Care. It is an occupation considered by some - including most of our clinical colleagues - as bizarre or even perverse. Yet, for us, it is an inestimable and most humbling privilege.

We spend our time with people facing the unwanted and uncomfortable. The ragged edge, where every experience is interpretable as a suffering or an opportunity and where the uncertainties may become the ingredients of conquests. However, the intimate details are seldom known to professional intruders such as us. We come, say a few things, and go. The hours and days of attrition go unmarked. We are inclined to see our brief encounters as the fulcrum of a family's day (Bruce and Roy were a family). It is only when we see behind the curtain of their universe that it is so clear how peripheral and on occasion inappropriate our actions were.

Every death is unique. To say that one is better than another would be ludicrous, but Roy's and Bruce's story gives us an opportunity to put our thanks and a few thoughts in print. They represent, if you like, a type: a death in which there was much life, and a separation

which, by its coming, led a relationship to deepen probably beyond what it would otherwise have been. In other words a good death: one in which tasks were fulfilled, relationships resolved and meaning found despite the meaninglessness of a young life lost.

We would like to say three things: First, this book stands in its own right. It is the journal of a relationship that is self-validating, but has needed to be formalised, as much as anything because the process has helped Bruce to make sense. In that process, we also have the opportunity to reflect and make sense. That is the challenge to each reader. What an encouragement to each of us as fellow travellers to experience the humour as well as the pain of Roy's passing. We also see that quality is indeed a changeable thing and that the true span of a moment is determined by what is done with it - half the narrative is devoted to the last days of Roy's life.

Secondly, as professionals, this account is remarkable in that it confirms so much for us. It shows all the things that we say and teach: dying is a process, not an event; letting go may take weeks or months, but remains very much in the hands of the patient; time is an elastic thing (compare the pace of the accounts about the world trip with the hours around the death) and so on. What is clear to us at least, is that we have no place attempting to manipulate that process - no matter what we do, someone dies when they die and takes the time they need and that's it. Our job is to create the decision space and the encouragement to take risks, and to wring every last drop from the time that runs through the fingers.

Finally, thank you, Bruce, for keeping diaries, for putting them in print and most of all for having permitted us to contribute in some small way to Roy's care.

*Dr. Rob George was Roy's Community Palliative Care Consultant.
Vicky Robinson was one of the Palliative Team's Community Care Nurses.*

GLOSSARY
of
medical terms used in this book

AIDS

Acquired Immune Deficiency Syndrome: AIDS itself is not an illness, but a term describing the varying collection of infections and illnesses (the 'syndrome') which result from weakening of the immune system by the virus known as HIV. The pattern varies from individual to individual. A person is not said to have AIDS until one or more of the typical infections takes hold.

AIDS-related illness

See 'Opportunistic Infections' below

AZT

Zidudovine - the principal anti-viral drug of the time, believed to inhibit the effect of HIV on the immune system. A powerful, toxic substance with potentially dangerous effects: damaging or destroying T-cells, for example, and having debilitating side-effects such as headaches and nausea.

CMV retinitis

This is one version of the CMV virus (see below) which can attack various of the body's organs and systems. This one simply destroys the retina progressively and leads to blindness.

Cryptosporidium

One of the opportunistic infections typical of AIDS. See 'Opportunistic Infections' below.

Cryptosporidium, actually untreatable, in the gut virtually destroys the body's ability to take nourishment from food or retain anything in the stomach. It also causes chronic diarrhoea. It can affect other organs too.

Cytomegalovirus (CMV)

One of the opportunistic infections typical of AIDS. See 'Opportunistic Infections' below.

CMV can affect various organs and parts of the body. Its typical activity is on the retina (where it leads to blindness) and in the gut. High-toxicity drugs like Ganciclovir and Foscarnet were thought to inhibit its progress.

Foscarnet

A high-toxicity anti-viral drug (see CMV above). Administered with additional fluid over several hours to protect the kidneys.

Ganciclovir

A high-toxicity anti-viral drug (see CMV above).

Heparin

Chemical which prevents blood clots blocking the Hickman Line.

Hickman Line

A plastic tube inserted into an artery near the heart and

protruding from the chest. Used for the direct introduction of intravenous (i/v) drugs in preference to frequent injections by needle.

HIV

Human immuno-deficiency virus: the viral infection which attacks and progressively weakens the immune system leaving the body profoundly vulnerable to 'opportunistic' and other infections. Infection occurs through direct introduction into the bloodstream from an infected person, through unprotected sex or open wounds, sharing of infected needles, or through transfusions of infected blood. There is still some controversy as to whether or not the virus can be transmitted via saliva, genital fluids or sperm.

Hyoscine

A drug used to control diarrhoea but inclined to cause hallucinations in some patients.

Kaposi's Sarcoma

A virulent skin cancer typical in the later stages of acute immune deficiency.

Midozolam

Injectable sedative like Valium, but very quick acting: excellent for distress, discomfort, agitation when the problem is not physical pain.

Opportunistic Infections

The infections typical of AIDS all result from viruses resident in the normal, healthy human body, which are suppressed by a healthy immune system. As the immune system is weakened by HIV, these viruses assert themselves and take the offered 'opportunity' to cause extensive, often terminal damage. For some of them there is no known treatment. These are collectively known as 'AIDS-related' illnesses.

A person with HIV is also, of course, much more vulnerable to the ordinary infections which can attack us all, and a simple cough or flu virus, for example, can have very serious consequences.

Palliative Care

The medical specialism concerned with the treatment of symptoms and the management of pain in chronic or terminal illness. The primary aim of palliative care is the comfort of the patient rather than the treatment and cure of disease itself.

PCP

Pneumocystis carinii pneumonia: this is one of the commonest, early opportunistic infections of a body with an immune system weakened by HIV. It causes coughing and irritation, but is amenable to treatment with Pentamidine and other drugs.

Pentamidine

Drug used for the treatment of PCP (see above)

Steroids

Drugs offering short-term quality of life, but in the long-term could cause problems or shorten life by causing vulnerability to infections.