

4: ISOLATION

“Isolation is aloneness that feels forced upon you, like a punishment. Solitude is aloneness you choose and embrace. Great things can come out of solitude, out of going to a place where all is quiet except for the beating of your heart.”

(Jeanne Marie Laskas, Writer, The Washington Post)

Isolation isn't an experience everyone with TB will go through. For those that do, it can be a difficult and emotional time. TB is a social disease. When someone is found to be infectious with TB, they may need to be isolated to receive treatment and prevent further transmission of infection. Generally, after a couple of weeks of treatment, you should no longer be infectious.¹ However, as discussed in section three, this doesn't mean that you are cured, and full treatment will take longer.

For some cases of TB, isolation is considered an effective method of infection control. This contrasts with earlier treatment methods when consumptives were sent to the old TB sanatoriums. People lived together - sometimes for months - in well-ventilated rooms. Sometimes TB sanatoriums were in beautiful surroundings in the mountains or by the side of the lake.² Plenty of

fresh air was the order of the day. It was more like a holiday than a hospital.

Times have changed. Instead of living in this sort of community, 'isolation' now means just that.

HOSPITAL ISOLATION

Many people who have been through the hospital isolation experience say that it is the hardest part of having TB. There is a lot of time spent thinking - hence the size of this section.

Isolation is undergone in a negative pressure room or a room with a closed door away from other patients (this is the preferred method of isolation in hospital). The safest form of isolation is the former. A negative pressure room is a room where the air pressure is lower than outside the door. This means that air can only blow in and not out. If your hospital is very modern, you may not even be aware that there is a mechanism creating this lowered air pressure effect. The mechanism is usually set in an outer wall.

If your room is a negative pressure room, and the weather is very warm, you will not be able to have a fan. The air pressure in the room would be affected and blow infectious TB bacilli under the door.

The air pressure doesn't feel any lower, and the air doesn't seem 'thin' like some people might imagine. In fact, you don't notice it at all.

As standard, negative pressure rooms have two doors. Beyond the door to the room itself there is usually another smaller room or chamber, and then a door to the ward.

The wearing of masks by people visiting is compulsory, and the masks are of a special type. The perforations are smaller than those found in standard surgical masks. If the holes are smaller there is less chance of breathing in any TB bacilli.

The isolation room is pretty normal by hospital standards. Adjacent to the room is a shower or bathroom and toilet. The win-

dow cannot be opened as it will affect the negative air pressure.

Isolation does not mean being entirely cut off from people. In many cases, you will be allowed to have visitors, and the hospital will keep a record of their names. They will be told that by coming into the room they are putting themselves at risk and are left to make the decision for themselves. A record of their names is kept so that, if any of them become infected, effective contact tracing can be carried out.

Visitors may also be required to have a Heaf test, give sputum samples or have chest X-rays to make sure they have not contracted the disease. It is unwise to have pregnant women, children, immuno-compromised or elderly people come to visit you. If these people really want to visit they should be clearly informed of the risks.

HOW LONG MIGHT I BE IN ISOLATION?

For some, the TB experience is worsened not by the disease itself, but by the hardships and loneliness of isolation. Isolation may last a long time. Those who have sensitive tuberculosis may only require isolation for two weeks. Others with multidrug-resistant tuberculosis may require longer because the drugs used to treat the disease work slower than the first line treatments.

If you are isolated, your doctor should be able to give you some sort of answer as to the length of stay. If you have standard TB and are compliant with your medication, the doctor should be able to give you a pretty good answer. It does help to know how long you are going to be isolated for. If you can see the days and count them down, it seems to make the whole experience easier. Eventually, you will see light at the end of the tunnel. For those who are immuno-compromised and have standard TB or have multidrug-resistant TB, the stay will probably be longer. It might also be harder for your doctor to give you an idea as to when you may be discharged.

Most doctors, particularly in the areas where there is a high incidence of the disease, can be quite precise about length of stay. However, there are regional variations in discharge policy and as a result your discharge may be delayed.

THE PSYCHOLOGICAL EFFECTS OF ISOLATION

Isolation carries its own unique set of coping problems. There is little written about the subject in relation to tuberculosis and the psychological effects. However, there is a study of people placed in isolation following a bone marrow transplant.³ Isolation is necessary whilst the transplant is ‘taking’; during this time the patients are at risk from a variety of infections. This is because their immune systems are artificially suppressed to prevent rejection of the transplant. Note that they are isolated to prevent them from being infected, rather than to prevent them infecting others.

In considering a 14-30 day period in isolation,⁴ the study found that patients suffered with depression, anxiety and disorientation. In addition, some patients complained of difficulty in concentrating. They also experienced odd sleeping patterns and a feeling of loss of control which could cause mood swings.⁵

There are many similarities between both experiences of isolation. The major difference between the two is that bone marrow transplants are planned, and individuals have some time to prepare themselves, mentally, prior to the procedure. Having TB isn’t a planned experience, and the individual is seldom prepared for what follows.

The study further states that: “Patient’s concerns are health, family, marital attitudes, financial worries, sexual and social activities, job and daily life, self image as well as the concerns about the disease itself.”⁶ Patients describe the experience as

being in a state of 'limbo' or going 'stir crazy'. The report recommends that patients make structures for themselves in 15 minute blocks of time, requiring them to do their own bathing, and formally schedule a time for watching television, making phone calls, exercising and resting. The authors encourage patients to bring in furniture, computers and other items from home that might increase their comfort and help to occupy and structure their days.

ISOLATION AND YOUR DIET

Spending time away from foods that you normally cook and eat can be hard. Hospital food is well-balanced and planned by dietitians. Jane Rowntree, a senior dietitian at St. Mary's Hospital, London, understands the difficulties: "Some people have food brought in for them. If they do, then it might help to speak to a dietitian. The majority of people who have food brought in for them end up with chocolates and that sort of thing which aren't the ideal thing that everybody needs at this time. The thing to do is work out what you want from the hospital menu and what foods you want brought in to you. By eating both, you should get the full spectrum of nutrients you need.

"The balance is important because TB, like many illnesses, can cause weight loss and a loss of appetite. Athletes have extremely healthy diets and extremely healthy appetites: they eat lots of high carbohydrate foods like bananas, rice, pastas, but these are not very energy dense. Choice of diet is clearly linked with your appetite and what you can manage at the time. If you have got a very good appetite then great. You can eat those sorts of foods, including fruit and vegetables, as well. If your appetite is very poor, then obviously you don't want to go for these foods alone because you don't get enough energy from them. You may have to add in some of the things that wouldn't usually be considered

particularly healthy: fatty foods for instance.”

If your appetite is very poor, it is still possible to obtain the nutrients you need from nutritional supplements. The type of supplements on offer vary; some of them are what are known as ‘complete’. That means that you can actually live off them. Others are more specific and are given depending on the problems that you are experiencing with your food. Some of them are designed just to give carbohydrates, some to increase body mass, and others to provide vitamins and minerals. These have a vital role in providing us with the nutrients we need to aid our recovery. If you are having problems with your food, ask to see a dietitian.

ISOLATION AND EXERCISE

Isolation rooms are often very small. However, if you feel well enough you should try to do some exercise. You can do this even if your room is not big enough for exercise equipment. Ask to see a physiotherapist who will be able to discuss a suitable programme with you. It is helpful to exercise whilst in isolation to keep some muscle tone. If you are not moving around very much, this can decline rapidly. Psychologically, it does feel like you are doing something to help yourself, particularly when you feel that you have lost control over your life. This returns a degree of control, just as dietary choices do. When you have TB, there is no better feeling than realising that you are putting on weight. If you are taking your medication you must be getting better. If you are getting fit as well, this is a bonus.

ISOLATION IN THE COMMUNITY

Isolation in the community means, in a nut shell, only having transient contact with other people. Mentioned as above, you should avoid women who are pregnant, children, the elderly or anyone who may be immuno-compromised. This can be difficult if

you rely on support services such as day centres: you may not be able to make use of these. You may also be advised not to use public transport, bars, clubs or restaurants for a while. This can be hard, but is a necessary precaution.

This form of isolation in the community is only temporary. If you take your medication as prescribed then you will eventually be able to lead a normal life. Your doctor will tell you when you can socialise normally with people again.

DIARY: ISOLATION

I had become so ill that hospitalisation was necessary and, because of my illness, this meant isolation. The side effects of the medication were extremely unpleasant and this, coupled with the psychological effects of isolation, made for a very disturbing time. My case was very severe: MDR TB is still quite rare in the UK.

SUNDAY 13TH AUGUST 1995 I arrived at the hospital and went to the casualty department. I sort of ‘floated around’ when I arrived. I wasn’t really sure what to do or what they were going to do to me. Eventually, I was put in a room away from everyone else. I sat on the couch which had no cover, just naked plastic. I would have liked to have laid down, but the grease stains left by the hair of the last occupant put me off. An hour and a half later and still no one had come. I looked to the wall for a nurses call button; there wasn’t one. I sat cross-legged on the couch.

Eventually, a nurse came in and gave me a mask which she asked me to wear. I carried my own bag, which seemed to get heavier and heavier, whilst she walked a good four metres ahead of me. I was feeling so bad. By the time we reached the ward the

gap had grown to about ten due to my exhaustion. She told me to stand outside the ward and left me by the door.

I was greeted by a nurse who seemed more pleasant and she showed me to my room. It wasn't a negative pressure room.

Once I was in the room, a nurse came in wearing one of the masks. She had brought some tea and toast with her. She told me that the doctor would be in to see me soon and that I would be moved out of the room to a real negative pressure room...when the builders had finished working on it! She left, and I was alone again, my head propped up by a couple of thin pillows with clean pillow cases, thank God.

Eventually, the doctor came. He was obviously tired from having worked all weekend. He told me that the doctors and nurses in the casualty department had been worried about me being there. The radiographers also didn't feel sure about me attending the x-ray department because of possible infection. I asked him questions about my potential problems: he told me that he didn't have any answers for me as he had only come to clerk me in. I asked him how he felt about being in the same room with me. He said he was apprehensive. I thanked him for our chat: it had been a good half hour long.

I must try to let go. There is only so much I can do, and the situation is out of my control. I must try to sleep. I have taken a sleeping tablet and it is starting to work.

MONDAY 14TH AUGUST 1995 A cup of tea and a couple of slices of toast greeted me, but before I could eat anything another nurse had come in to take my temperature. It was 38.2 °c, quite high for me in the morning. It was usually high at night. I had my breakfast and after that another cigarette in anticipation of the consultant coming round to see me.

I had fallen asleep by the time he arrived. My neck was wet from

sweating, and when I woke up I found that I had soaked my pillow. He examined me thoroughly whilst his entourage watched: he told me that he was not convinced that this episode was down to TB. The nurse took the two samples of sputum I had produced that morning, and the consultant et al. left the room. I then rediscovered the delights of daytime television.

It is so hot in here. I cannot open the window: it has been nailed down. I am not allowed to have a fan as it would affect the pressure in the room and blow any tubercle bacilli out through the door when people came in.

There is a fly in my room and it will never get out.

TUESDAY 15TH AUGUST 1995 I woke in a still, airless room. I had my usual cup of tea and a cigarette. The weatherman says it is going to be hot again today. I am at day 19 and still no news. I don't know whether I have this disease or not. I walked over to the window to get my urine bottle; next to it lay the fly. Dead.

A senior radiographer came crashing through the door with a machine resembling a big white robot. She told me that she was the only one who was prepared to come. The other radiologists had declined. I felt hurt by this. Still, she stayed for about ten minutes and chatted.

I am so busy wondering what is going to happen next, I am finding it difficult to live within the moment. Still, perhaps in here the moment is not the best thing to think about. It is so dismal. I think about how that one telephone call came out of the blue back in July. My whole life was decimated in a few seconds. Perhaps that is why I am so scared of what will happen next. You just don't know what's around the corner.

I could hear and see a group of doctors through the slatted glass

window in the door. They talked for a few seconds before they came in. I was getting impatient: they hadn't been able to get any test results. I showed them my contempt by being abrupt and rude. I had a rant about it but the doctor interrupted me: they had got my test results back that morning.

These confirmed that I had multidrug-resistant tuberculosis.

WEDNESDAY 16TH AUGUST 1995 I sat alone crosslegged on my bed. It was 32 °c outside. The dirty brickwork of the enclosed square of buildings outside my window looked beautiful. How I would've loved to have been out there.

Later that night I was moved to my new room. It was more bearable: they had knocked down a wall and I now had a bathroom. It was quite large as it had been a communal bathroom before. The shower didn't seem capable of any real pressure - it was reminiscent of an old man with a prostate problem urinating. However, I was grateful for the small amount of cold water the shower provided (it didn't do hot!). One of the other benefits of the bathroom was that it was quite cool - it didn't have much of a window other than a really small one over the toilet. I could see me spending a lot of time in the bathroom hiding from the heat.

THURSDAY 17TH AUGUST 1995 The day began as the night had begun, being given a small plastic pot about a quarter full of pills. It takes me a while to swallow them all, but I have become a bit of an expert at it.

I am very confused and not really in control of anything right now. I am struggling with chest pain and breathlessness. The heat isn't helping. I have been promised air conditioning, but everyone else seems to want this, the summer being a particularly hot one. The units we require are completely out of stock. In the meantime, I am stuck in my sauna.

The consultant came to see me. My partner and a few friends were visiting, and he asked them to leave for a while. One of the sputum samples I had given had come back as smear positive. My first positive sample: I am now officially infectious. The good news is that the MDR TB is sensitive to the second-line drugs I was taking. I have a chance. Well, that is something I suppose.

FRIDAY 18TH AUGUST 1995 I was cold - tossing and turning and still drowsy from the drugs. Eventually I woke up: I was lying in a puddle of sweat. My sheets were soaked, right down to the spenko mattress that had been put on my bed to make me more comfortable. My sheets were changed for the umpteenth time. There were no pyjamas left, so I had to wear a gown. I couldn't get back to sleep, so I tidied my room and had an extremely cold shower.

I am beginning to let myself go and look a bit scruffy. I have to pull myself together. I am scheduled to have a broncoscopy today. That means they are going to sedate me and put a fibre optic camera down into my lungs, have a look around, and take a few samples. I have never had this procedure before. I am terrified that there will be a drowning or suffocating sensation when they pass the camera into my lungs.

A few hours have passed and although it's not as hot as yesterday, it's still warm; I haven't been able to eat or drink anything since I had my breakfast this morning. I am feeling very dehydrated at the moment. I waited until 4pm and they took me down to perform the procedure. It was great just to feel the air as I walked. It felt different, moist, unlike the air in my room.

When the staff saw me coming I could hear them saying: "He's coming, he's coming", and they frantically put on their masks. The sister of the unit had briefed me the day before on what the

procedure would involve. This time she wasn't wearing her uniform, but an outfit that resembled a space suit, and so was my doctor. Both had special respiratory equipment. The sister then led me quickly to the bronchoscopy suite. I lay on the couch and co-operated with their requests. I could tell this sister wasn't going to take any nonsense from anyone. I wasn't going to mess with her. Besides, she was bigger than me and I didn't want to wrestle with her in my condition. I was relying on both of them to keep me safe during the procedure.

The first injection was to dry any secretions, then an injection of the sedative. I looked at the wall. It didn't feel as though it was working. I thought about the panic when I had arrived at the bronchoscopy suite. My world turned to darkness and I didn't care; and I didn't remember...

I stirred; my mouth was parched and I wanted a glass of water. However, I couldn't move let alone summon the strength to push the nurses call button. I eventually managed to push off the oxygen mask. My left nostril was very sore. It felt blocked. Apparently, they carry out the procedure mainly through the nose and not the mouth.

I had some difficulty swallowing, although as the hours went by it got easier. My strength was coming back.

I settled down for the night. I had taken most of the medication and was finally enjoying the new air conditioning unit that had been fitted that day. Though, of course, I was re-breathing the same air.

SATURDAY 19TH AUGUST 1995 I want to keep as busy as possible. I wrote a letter to a little girl who I don't know, who had drawn a picture of herself playing with her hula hoop in her garden. A friend of mine had been baby-sitting and had told her about me being here. I was touched: it was so sweet.

I am going to stick it to my bedside cabinet if I can remember to ask the nurse for some medical tape. They usually have some in their pockets.

There is a new addition to my environment. A yellow bucket full of a strange solution. The nurse bought it in earlier. I am supposed to put all of my dirty dishes and cutlery in this bucket. I think this may be a bit of an overreaction. My disease is airborne; you can't contract it from cutlery or dishes.

It is 1.45am and I have spent the last hour pondering the fact that all of this struggling and fighting for the basic human rights that have been taken away from me may be pointless. I am probably going to die anyway. Why do I bother fighting? I have no quality of life here: I can't even see my partner. I just lay here or sit and look at the wall. Even television has become difficult; it's not as if I'm even watching it when it is on. My concentration span seems so limited.

I need a reason to live and I can't find one - particularly if I have to spend the rest of my life in this room. Writing it down seems to provide some solace; when I am writing I am talking about things that have already happened. When I am left alone with my head, I can only try to imagine what will happen next. Unfortunately, my imaginings are distorted by the medication.

I am going through feelings of guilt, almost as if I am a naughty child again. I feel as though I am being punished for something; it makes no logical sense because I've done nothing wrong. However, this is precisely how I feel.

I'd asked the nurse earlier if I could stop the treatment and just be allowed to die. The chances of my survival seem so small, and I may remain infectious for a long time. If I have to spend the rest of my life in this room there is no reason left to live. I don't think

I am going to get out of this.

I've never been in trouble with the police, so I've never spent time in a cell. Yet this is still a prison. Unlike most prisoners who can look forward to the time of their release, I am told that it is uncertain that I will ever leave this room. They keep on telling me how important it is for me to keep my head together - but I don't have the information to make decisions about my life anymore, and neither do the doctors, or so it seems.

The nurses come in and ask if I am "OK". What can I say? "No?" They won't know what to say to that answer, so I just say "yes", and although they know I am not telling the truth, it seems to make them feel better. There really are no answers to this one. I have played all of my cards. I could gamble and make the effort, or I could just let go like some awful plate spinning act, and wait and see what happens.

Fighting to survive is encouraged by other human beings: "That's the spirit," they say. They forget that sometimes this is unrealistic. If I die, will people feel that I've let them down? On the other hand, many people believe that you should only be allowed to die if you are in the end stages of terminal illness. I seem relatively well, all things considered. I don't know if the doctors are trying to tell me that a storm is brewing; are my test results some kind of image in a crystal ball?

The criteria for my release here is a negative culture. It is possible that I may never have one. There are also no firm guidelines on what the criteria should be. Some authorities state that having no fever and producing three negative sputum smears should be enough to release me.

My doctor tells me I am the only patient he knows who has had MDR TB and AIDS together. I have no doubt that he wants to see

me get better, however I do feel a bit like an experiment. I feel very drained at the end of another day in this room. It has been eventful for a Saturday. Weekends here are very quiet usually.

SUNDAY 20TH AUGUST 1995 I had another night sweat last night, around about four in the morning. The nurse came in to change my sheets. The spenko mattress had absorbed most of what I had sweated out.

The builders are working around people. There aren't the facilities to isolate people properly here, and they are trying to build bathrooms and make communications to the outside world available. The machine that is set in the wall whirrs away. The room is filled with a constant hum. There is still no hot water, and I had another cold shower today. At the time there was a domestic in my room, and it was hard to find any privacy behind the shower curtain.

A friend had bought me some red roses the other day and they have died very quickly because of the heat. It is another hot day today.

MONDAY 21ST AUGUST 1995 I woke up at about 8am. The ward manager came into my room and started to talk to me about being moved. No one had told me anything about this. I wasn't aware of any move. Apparently, they want to build a proper air conditioning and air filtration unit in here. Once again they are building around me. I will have to be moved into another room. I shall lose my bathroom and my toilet for about three days; that is, in real time. As this is a hospital, I'm probably looking at more like five. Back to the world of commodes and pee bottles.

Apparently, I have a serious illness, though today I'm feeling very well. I haven't even got a temperature. I told the ward manager in a defeated manner that it would be okay to move me for a few days. It seems I have little choice.

Later, two men came into my room and started measuring things up. They noticed a strange duct in the ceiling that disappeared into the bowels of the building and went God knows where. They didn't stay long after flitting around with a measuring tape and discussing the positioning of the unit.

A few visitors came to visit me after lunch. Whilst they were there, a domestic came into my room. She had with her a mop and a bucket. In the bucket was a noxious solution that we could smell as she walked through the door. She dipped the mop in the bucket and started to wash the walls. It wasn't long before I got up and demanded to know what the stuff was. Hycolin Phenolic 2%. The bottle also carried a skull and crossbones warning that it was harmful and should only be used in well ventilated spaces. I asked her to get a nurse right away, and then proceeded to verbally crucify him as he walked through the door. My friends by this time had been affected by the fumes and had to leave to room. I, however, had to stay. I walked around like an animal being gassed, trying to find a pocket of breathable air. There wasn't one.

I demanded to know who had ordered the use of this crap on my walls. They couldn't tell me. My eyes started to itch and my skin and throat were burning. The doctor came in to see me; my windpipe felt tight, but he couldn't hear any wheezing and said that I was OK. I completely lost my rag. No wheezing! I've got TB!! Did he really think it was a good idea to use this stuff on the walls? Who authorised it? Was it really necessary? He couldn't (or wouldn't) answer my questions. I was so angry; I suppose in a way it gave me the excuse I needed to release a lot of pent up anger. The barrage ended with me being downright rude: "My friend, you are an arsehole, get out!" As he left he turned to say something, and I shouted: "And don't think you are going to get

the last word!" He thought twice about whatever he was going to say and left the room.

I felt better after shouting at the doctor, although I later wondered whether I'd hurt his feelings. That is, if doctors have feelings. They must see so much suffering I suppose they develop a thick skin and learn to deal with these things.

Two nurses came in. Damage limitation perhaps? I told them that they didn't care about me, that I had AIDS and MDR TB and was going to die. It made no difference to them whether I lived or died. How could they know what I was going through? One of the nurses told me that the things I was saying were hurtful. I told her that I was saying those things because I was hurting.

This was my air and they had polluted it. My throat was still burning. I demanded that an accident form be filled in. I wanted them to acknowledge what had happened.

I tried to sleep this afternoon, but people keep coming in to see me. To be frank, I'm getting sick of all these visitors.

Later, a doctor came to see me. I don't really know what he looks like because of the mask. I have to imagine what the rest of someone's face looks like and try to identify them by their hair or glasses. I told him about the way I had treated his colleague. I felt that I must say sorry to him. This would be the second time that I would have to apologise for my behaviour since coming here.

A nurse came in after he left with the accident form that I'd requested. We sat together and chatted for a while. She apologised to me for what had happened. It seems the nurse I had been rude to had been very upset. She has been working long hours for a few days - today is the last day before her days off. I told the senior nurse that I must apologise to her as well. The nurses are finding the whole MDR TB situation hard to deal with. It's completely new to them.

Later, the nurse I'd been rude to came in. She brought me a cup of tea. I turned down the bizarre television set that has a mind of its own. If you turn it up, it gets uncontrollably louder; if you turn it down, it becomes completely inaudible. I apologised and she accepted immediately.

I know that she and the other nurses have tried to do their best for me. We chatted a little while longer, and when she left I felt better. I really didn't want her to be upset while she was away.

TUESDAY 22ND AUGUST 1995 I lay awake in the half-light. The time was 5am. These days I usually wake up about this time. I don't seem to be covered for the whole night by the sleeping tablets. I don't really remember the last proper night's sleep that I had. I smoked several cigarettes and had a couple of cups of tea.

One of the night nurses came in. She didn't really know what had happened the day before. She knew that I'd had a 'go' at a few people, including the doctor. She told me that he was quite upset by the episode. For some reason, I was feeling reluctant to say sorry to him now.

The feeling of being punished for something that I haven't done has come back: a naughty boy locked in his room. I got up and had a cold shower. I could only wash parts of myself. My flesh is not willing to be plunged under freezing cold water at this time in the morning. One of the night nurses came in and changed my sheets, and I lay there waiting for whatever might happen next. I am sick of the drama, I just want to be left alone. I certainly don't want to be here. I am isolated, but there is no privacy at all.

The bucket that was left in my room to put cutlery and dishes in has been taken away. Like I thought, the doctor says it isn't necessary.

I became quite agitated this afternoon. A friend came in to see me; she could see that I was in a lot of emotional and physical pain. I haven't had any psychological support for nine days due to a staff shortage. I think that I now know what is meant by the phrase 'climbing the walls'.

I sat down on the floor beside the fridge on the other side of the room with a cup of tea and my cigarettes, purely to see the room from a different perspective. It seemed to work for a while. If anyone had walked in they might have thought that I'd gone completely mad. They might have been right.

I'd been offered valium earlier that morning, but refused it. I really want to try to keep control, but the mental pain is getting worse, to the point where I'm writhing around in bed. I decided to take the valium - 10mg - quite a large dose. I became muzzy-headed and eventually fell asleep.

I was woken by the consultant. I still felt confused from the medication. He had the results of the bronchoscopy done a few days earlier. He had found an area in my left lung that appeared to have cavities forming. He said it was quite inflamed, which indicated that the TB was more active than he had originally thought.

Well, it's time for me to try and settle down. The valium has run its course, and the temazepam will induce the next period of oblivion. Sometimes I feel that I would like to be sedated all the time. This might even be an option. The only thing that scares me is that I might not wake up again.

I don't know how to deal with this - this is the worst thing that has ever happened to me.

WEDNESDAY 23RD AUGUST 1995 If there is a God - I hate him.

THURSDAY 24TH AUGUST 1995 The nurse came in to wake me. The time was 7.45am; I was still tired and would have liked to go on sleeping, but the workmen had come to fit the air filtration unit. I had to pack all my things into carrier bags, taking gulps of tea to wake myself up at the same time. They say it will be only for a few days. I have been moved to another room: Room 16. Unlike my last room, it doesn't have a double door. I don't think it is a negative pressure room, although judging by the walk, it's the furthest room away from the other patients. I have no shower or toilet here. Once again, it's back to the dreaded commode and the urine bottle, and strip washing at the sink. I won't be able to have a shower for three or four days. There is very little dignity in all of this. I had come to be grateful for the dribble of cold water from the shower and for having a toilet of my own. One positive point: I get a different perspective of the world and the chance to breath some different air. My idea of a treat these days!

I'm confused enough without being constantly moved around. In addition, the team of nurses looking after me will change. I had managed to develop some sort of rapport with the other nurses, though it was a bit strained at times. Now I will have to start again. More new faces - and more new names. All wearing masks with only the eyes visible. It's amazing how much we read into facial expressions. So much is communicated with a smile. No one smiles at me any more - and if they do I don't get to see it.

I have received no psychological support since I have been here. I have tried my best to manage, but sometimes I really lose it and have to be take valium to calm myself. I don't like mind-altering substances. I want to be in control.

Today, however, the psychologist came to visit me. I was too tired to talk, so she left. People keep coming and going, including

my consultant. He says that the duration of my stay raises issues of civil liberty, and that they couldn't keep me here forever. He wants me to live in some kind of 'isolation in the community'. He doesn't believe it's a good idea for me to go back home or to live with my partner. I can't believe that our three-year relationship is going to take this turn. It has become impractical in the face of infection control.

Ironically, the housing department has so far turned me down. I am hoping the Public Health Department can emphasise to them the importance of re-housing me. I don't want to move, but I don't want to infect my partner either.

I don't know how I'm feeling at the moment. I am going to have to rebuild my life. This is hard when I don't know how or where I am going to live.

The most important thing is quality of life, and I need to exercise freedom of choice. I can't help feeling that so much is being decided for me without my consultation. I don't want to be put on some council estate, forgotten and struggling to survive on benefits.

A little later in the evening, the consultant came to my room. It seems I have misunderstood: I may be here for a very long time. It's still possible that I may not respond to the treatment; I may remain infectious. I may even die here.

Once again I feel devastated. My hopes were so high. I thought I was seeing a light at the end of the tunnel. It was all my imagination. So, I've slipped back again into my world of hopelessness. More valium please?

FRIDAY 25TH AUGUST 1995 My head is still swimming from the valium and temazepam I took last night. I've completely filled the pee bottle and don't know what to do with

it. I'm so confused. There is a pain in my chest and it won't go away.

I can't go on like this. I've told the nurse that I'm going to refuse treatment and have gone on hunger strike until something is done. They have got to give me a reason to live.

I am homeless. My three-year relationship is finished. I have nothing to go back to. Everything has been destroyed. Yet deep down I want to survive, and I don't care what I have to do.

I have to wait 'til Tuesday before I can speak to my consultant again. I'm going to try to get written confirmation that they intend to re-house me. I can't relax until this is done. I don't know what's going on anymore. I am not convinced I'm being told the truth.

I am sick of other people organising my life. I have taken more valium. I want to be valiumed out this weekend 'til Tuesday. These people are killing me.

SATURDAY 26TH AUGUST 1995 Perhaps I took a little too many sedatives last night. I feel pretty groggy. I stood on the bed to open the roller blind and wobbled a bit; perhaps this sedation business isn't such a good idea after all.

Everyone is on holiday this weekend - it's a bank holiday. Looking out of the window it seems that the weather we have had over the last few weeks has gone on holiday as well.

One of the nurses went to see how the work was going on my room. I may be able to move back in today, but as everyone knows builders and deadlines don't always go hand in hand. I really hope I can move back. I haven't had a shower for three days.

Thankfully, she came back with good news. I can move back in today. We had a chat for a while; I expressed the unfairness I felt at being here. I feel I have lost all sense of dignity. I used to think that the worst thing that could happen to anyone was to be locked up. Well, now it's happened to me and it is hell.

Apparently, a few days ago I had frightened the nurses: whilst under the influence of a large dose of valium, I asked someone if I was dead. I couldn't remember how I'd died. Was it a car crash? My mental state is deteriorating. I am feeling increasingly paranoid.

My room has a telephone now. It crackles a bit; not anyone's fault, just teething problems I suppose. The air extraction unit in my room has added to the white noise made by the negative pressure unit.

One of my visitors has brought in a personal stereo and some tapes. I'm listening to them now and it's lifting my spirits. I want to survive - I want to live so much.

SUNDAY 27TH AUGUST 1995 I sat around doing nothing today; just watching TV and trying not to think too much. My mind is my worst enemy sometimes. It causes me to say and do stupid things. Restraining tongue and pen is not always a bad idea. I was really horrible to one of the nurses yesterday. I told her that I could kill her if I wanted to: then what would they do? LOCK ME UP?! It had really frightened her, so I was glad to see her when she came in with a cup of tea for me. I reminded her of what I'd said and apologised. I don't know what gets into me sometimes. I find it hard to keep a grip on things.

I really don't know how to express the sadness. Between the buildings outside I can see a small square of sky with a few tower blocks in the background. I know that out there the world still revolves, and people are getting on with their lives. I know that if I ever get out of here, I'm sure I will be grateful for those little things that we usually take for granted: my own bed, my own tea mug, my cat.

I can't take the turmoil. It doesn't matter what anyone says to

me. Words mean nothing if you don't have your freedom. Oh, I don't know what I am talking about. I don't even recognise my own madness and confusion any more. I have to rely on other people to tell me when I've lost it. But who could be that honest?

MONDAY 28TH AUGUST 1995 I have never really liked bank holidays very much. That's probably my fault for not trying hard enough to do anything with them. My resolve is still strong, but not as strong as it has been. My imagination seems to run away with me. Am I expecting too much?

I had my traditional freezing cold shower this morning. I am doing my best to look tidy. Yesterday I even managed a few press-ups. I'm not going to push it today; I'll try and do some more tomorrow. I can feel the affect of them under my arms. Today I'm going to pay attention to my legs. Perhaps some running on the spot or stretching exercises. Tomorrow I might try some dreaded sit-ups: this is an exercise that I've never enjoyed doing because of the stomach ache that it gives you. Then I will go back to press-ups, afterwards the legs and back to the stomach and so on. Easy does it, and hopefully I will leave here with my muscle tone intact.

Perhaps I have lost all sense of perspective. I seem to swing between the paranoia of being locked up in here forever, to feelings of total euphoria. I sometimes feel like a worthless piece of shit, and that this episode in my life is going to have an unhappy ending. It is at times like this that I feel suicidal. That wouldn't solve anything, I know. I must try to think of ways to make myself feel better.

I have to be constructive and make the best possible use of time. I have decided to start re-building myself physically. I have a friend who is in the Queen's Guard who is going to devise a fitness programme for me. He is going to bring in some bar-bells for

me. I have asked the nurses if I can use the exercise bike that I noticed on the ward. They don't see any reason why not: it doesn't get used very much. If I do ever get to leave here I might have a bit of a body! I can make positive use of my time here. I am going to ask my doctor if I can have a sunbed!

TUESDAY 29TH AUGUST 1995 I think this is the first overcast morning since I have been here. I love the sun. Through the bars at my window I can see the cloudy sky and the old buildings of the hospital with a newer one in the background: the nurse informed me that it was a block of flats that was very popular for suicides. Cheers!

I am feeling a bit flat this morning. This may be due to the fact that I had 20mg of temazepam and woke up about 2am, my head whirring around with all sorts of things. I was given another 10mg of valium to help me sleep.

I am hoping that during the day the effects of the drugs will wear off. It may be an interesting day; the hospital springs back into life after the bank holiday weekend, and the consultant is coming around. In the meantime, I am going to try to keep to my routine by having a cold shower, cleaning my teeth, getting dressed and doing my workout.

I have just weighed myself and I have put on 1kg: I am now 61.1kg. When I was admitted, I was about 59kg. Very slight even for a skinny thing like me. I would like to be back up to my normal weight of 68kg which is what I was about a year ago. I have never been heavier than that anyway.

I had one of those chats for about 15 minutes with a nurse. Once again I went on about my fear of never getting out of the room. I pray to the God I hate that there will be some progress soon.

WEDNESDAY 30TH AUGUST 1995 After I got up, I did 15 minutes on the exercise bike and I feel surprisingly good. Perhaps there is something in this exercise lark after all. I like to try and shake out the 'cobwebs' left by the medication and sedatives they gave me last night.

I had a very unusual and moving discussion with one of the domestics who was cleaning my room. Her three-and-a-half-year-old son had been murdered. I found myself getting very emotional; it reminded me (temporarily) that I wasn't the only one having problems. You lose a sense of perspective when all you have is your imagination for company. I knew that underneath the orange mask she wore, she was smiling fondly at the memory of her child, sitting there on the edge of the bed with a duster in her hand. She shows no bitterness, she even believes it was an act of God. If it was, it fits in with my perception of Him, Her, It, Whatever. She says her life must go on.

I have used the exercise bike again; then ten press-ups and ten of the dreaded sit-ups in the way my friend has shown me. I am still waiting for the bar-bells to arrive.

I was half asleep when the consultant came in. He said that it looked as though I was getting better and that, theoretically, I could leave if I could find somewhere suitable to live. I suppose by 'suitable' he means 'safe'. However, I would have to live under similar conditions to the ones I am subjected to here until I produced a negative culture. Only then could I rejoin the human race.

THURSDAY 31ST AUGUST 1995 I woke up with a temazepam hangover this morning. I had my cold shower

and once again forced myself to do some exercise.

A little later, the magnitude of the problems I am facing began to dawn on me. I was unable to return home or to mix with other people and perhaps would never be able to go out again. What is going to happen to me? I am so frightened. Perhaps I shouldn't fight it; just accept that my life has been destroyed. If there is a future for me, it is likely to be very different. Today I do not feel that I am coping very well.

I have a slight pain in my chest which will hopefully pass. One of my visitors seems to know more about what is going on than I do.

Once again, I ritually close my orange blinds. I wonder if they will throw them away when I leave. After all, at the last room they took away the curtains. Blinds probably don't do very well in the washing machine.

The only time I seem to get any peace is when I'm asleep. This is so sad - I really used to enjoy life. Sleep was an inconvenient necessity that I endured, waiting for the next exciting day. Now sleep is something I look forward to.

I feel disorientated: a familiar feeling in an unfamiliar environment. What am I saying?

FRIDAY 1ST SEPTEMBER 1995 I open my eyes and look at the clock. I've woken up very early again. It's about 4.30am. The sleeping pills only seem to cover me for about four hours. I thought about getting some more valium and just kipping for a few more hours. Take it one step further: I could order loads of drugs and turn my room into a psychedelic pharmacy! But then I remembered the 'cobwebs' that the valium and the sleeping pills seemed to leave me with, and decided to listen to my body.

Before I got up, I pressed the red button for a cup of tea. The nurse who brought it in looked very tired from her night shift. She told me that things had really got moving since I'd been there. Doctors in general hadn't realised the potential problem that TB might present.

Fifteen minutes on the bike and a traditional cold shower. My stamina is definitely increasing and soon I will be able to use the weights.

The day is turning into a bad one: I can feel the anger building in me. The doctor who I'd shouted at the other day came to see me. I apologised. Then, minutes later, another doctor came to see me. I questioned him about when I would be able to go. He said that I may have to spend the rest of my life in this room. To say I lost it would be an understatement.

"If you are going to treat me like an animal then I shall behave like one!" With that, I threw a jug of water at him. This narrowly missed him and shattered on the radiator opposite. He left the room saying he would come back when I had calmed down.

I feel as though I have lost it, and have decided that I want to die.

SATURDAY 2ND SEPTEMBER 1995 The sedation has worn off. I can't sleep and they won't give me any more. There is no point in wishing for the day when I will be free again. I know that my being here is in the interests of public health. I don't know where I'm at. My profound determination to live turns into suicidal depression, and the swing happens in seconds.

MONDAY 4TH SEPTEMBER 1995 The usual pattern of me waking up about 4am, having had a night sweat,

and with a soaked pair of pyjamas and sheets has become familiar. Dazed, I generally sit there in my armchair whilst the nurses change my sheets.

I have had my work out. I've got my new weights now and I feel I am getting stronger.

FRIDAY 15TH SEPTEMBER 1995 For the last eleven days I have been in tortured limbo. A 'no-man's-land'. The living dead. I haven't worked out, written, read or done anything else. I have turned away visitors and I seem to have just withdrawn into myself. I don't know what happened. Perhaps I just blew a fuse of sorts. I don't think I have ever been that depressed before. Today I feel a bit more normal. Whatever normal is.

There are two men in my room; they arrived just after I woke up and have come to have another stab at fixing the shower.

The consultant came in next. I wasn't expecting to see him so early. It was about 8.30am. He is flying off to the United States today to find out more about this disease and wants to tie up any loose ends before he goes.

Apparently, I can be discharged when I have produced a series of negative smears. This seems much more attainable. It is quite possible that I can produce negative smears. Cultures are another thing.

I often worry about the potential for infecting other people. I don't know whether I could live with this if it happened. I'm looking forward to the consultant coming back from the US. He may have some good news for me. I must try to trust him; at times his actions seem draconian, but they are well intended. Faith, I suppose - a type of thinking I find hard to sustain.

SUNDAY 17TH SEPTEMBER 1995 Would you believe it! There has been an outbreak of scabies on the ward. Most of the nurses looking after me have it and have passed it on to other patients. On close inspection it seems I have it too. So much for isolation. I have been itching quite a bit, come to think of it. I feel so dirty already, what with the TB and HIV. I am filthy.

Once again, I'm finding it difficult to cope. I want to throw something through the window or make a dash for the door. However, doing this now may jeopardise any chances I have of being discharged. If I am co-operative now they may be more inclined to let me go.

MONDAY 18TH SEPTEMBER 1995 I have become so self-focused being here; I've been unable to think about anything else except my predicament. I have a friend who has been ill for quite a long time with a brain tumour. They tried to operate, but only managed to remove 80% of it. His chances of survival are not good, apparently. He is on a lot of medication which has made his face swell up. I'm told by my friends that it is hard to recognise him. They now know two people who are very ill. It must be very stressful.

I love my friend James dearly. I wish I could see him. I just don't know why this has happened to him. He isn't HIV positive like me. He is just a 25-year-old man with everything going for him. It's so unfair. Perhaps I deserve this disease; he definitely doesn't deserve his.

I dowsed myself in the lotion I'd been given to kill the scabies. Just another ritual I have added to my daily routine. I have to say it doesn't smell very nice at all. I've had to cover myself from head

to foot. All of my clothes have been taken away to be washed, and my sheets have been changed. Scabies - just another one of the lovely social diseases that I seem to be making a habit of collecting. In the meantime, I'm walking about holding up some very large pyjamas as I have no clothes.

My thoughts are racing. I keep saying it, I know, but I don't know what is happening to me. I feel like I'm in between two worlds. Neither dead nor alive. Is this what the Catholics call purgatory? Is it a punishment?

TUESDAY 19TH SEPTEMBER 1995 Not good today. Should I stop taking the medication? More questions for which I don't have the answers. I apply a funny sort of logic: if I am to spend the rest of my life in this room, then I think I would rather die. Of course, suicide is an option and crosses my mind frequently: I often think about how I might go about it. The thing that really holds me back is cowardice. I just can't do it.

After all these dark thoughts, my mind seems to dwell on the things I would miss. Then I yearn for them and become excited once more about being released. Suddenly, I feel quite hopeful again. It seems I swing wildly from the dreams of a new life to the nightmare of the old one.

However, I feel like fighting most of the time. If only out of curiosity to see what will come. In the meantime, there seems to be nothing but endless repetition.

WEDNESDAY 20TH SEPTEMBER 1998
My sunbed arrived today!

THURSDAY 21ST SEPTEMBER 1995 I woke up early and had my usual cup of tea and cigarettes, think-

ing about the day ahead. My hair is getting rather long and needs cutting. However, the hospital hairdresser can only do a blue rinse and set by all accounts, and I don't think it will suit me.

I opened the blinds when I was cleaning my teeth, and just stood there wide-eyed. There were two huge magpies sitting on the roof opposite. I could see right into their eyes. I felt so excited at seeing them that I spat out the toothpaste and rushed over to the nurses call button. I wanted at least one of them to see them. These things have become so important to me; the first day in isolation seems an eternity away.

I waited for the nurse to come, hoping that they wouldn't fly away in the meantime. One of them moved out of view as she came through the door. "Look," I said, pointing through the window. She was startled, to say least: "Don't show me that - I don't want to see one of them!" I was confused; she told me that to see one of these birds on its own was said to be unlucky and could bring great sorrow. Two, on the other hand, was a good omen. I had seen two. It is probably foolish to put faith in such things, but it certainly made me feel better.

Two of the doctors came to see me. Apparently my 'liver function tests' are abnormal. Not surprising really, considering the amount of medication that I am taking. One of the doctors examined my stomach. In his opinion there was nothing going on that was too serious. However, they decided to carry out a scan of my abdomen.

Come to think of it, I'd had some stomach pains over the last few weeks. I put this down to my new fitness routine and had blamed the dreaded sit-ups. The doctors also told me that they weren't sure if I was actually getting better. St range, because I feel okay. They say I should be smear negative by now but, according to the recent samples, this is not the case. If things haven't changed by

next Monday they are going to try a new drug.

I really don't want any more drugs. The doctor is going to consult another hospital about the new drug to see how effective it is. They haven't used it before here.

I have asked my friend to bring in my Polaroid camera. I am going to make a montage of my room. Although it's small, there could be a lot of good photos. I might be able to do something in the style of Nick Rhodes. He had a passion for distorted TV screens. At least it's something to do. One of the things I really hate is asking people for help when they may reply in the negative. I don't like being dependent on others, and I don't like the thought of them saying "no".

Later in the day, my partner came to see me with the camera. I experimented with a few pictures of the bars at my window, and other things that would remain evocative of my 'residence'. The world as I knew it.

FRIDAY 22ND SEPTEMBER 1995 Today has been pretty dull and uneventful, except that I have been told that there will be a case conference about me next Friday. I am not invited. I feel angry that I am not able to be involved with the decisions which are being made about my life.

Another week gone. I have tried to keep busy. The weekend is here; that silent time when the hospital seems to sleep, and those that work here go home to their own lives after interfering with everybody else's.

SATURDAY 23RD SEPTEMBER 1995 I have decided to try and have a 'be nice to Pauly day'. A day of sunbeds, fitness and rest. My hair is pissing me off! It hasn't been this long for ages, and I'm apprehensive about the blue-rinse

brigade. I've asked a friend to buy some hair clippers and I'm going to chop it all off.

Well, I've done it. I have no hair at all! (I got a bit carried away).

THURSDAY 28TH SEPTEMBER 1995

I hate this room. My window is so dirty; I can barely see the dismal view of the brick wall outside. In the distance, nothing moves on the motorway. There is nothing. I have to prop the door of the bathroom open with the handle of a mop. The drain in the shower stinks, and I have no option but to breath in the stench. I will probably catch something else at this rate. MDR TB, scabies - I hate to think what other possibilities lurk in here.

FRIDAY 29TH SEPTEMBER 1995

There is going to be a case conference about me on the ward today. As I shall not be present, I have issued a statement to be read by someone else on my behalf. This is to remind them that it is my life that they are making decisions about. I can't help feeling that the mistakes that were made at the beginning of the HIV epidemic are about to be made again. Everyone seems so frightened by the threat I apparently pose to others.

The conference started at around 2pm. I really don't know what was said. As far as I can ascertain, it amounted to nothing more than the people involved getting better acquainted. No real decisions were made. It has taken so long to get them around a table together, and yet the most important person, my consultant, wasn't even there. He is still in the United States. Once again, it seems, I shall have to wait.

The minutes have turned to hours, and I can hear the ticking of the clock on the wall. The time between each second seems to be

getting longer. I sometimes just lay here, my hopes fading, trying desperately to find the strength to go on. I have tried doing everything I can. It is possible I am going to lose this battle.

MONDAY 2ND OCTOBER 1995 Today could be an important day. My consultant is back from his fact finding mission to the United States. Let's hope he has some new ideas. This last weekend really dragged. I am much better physically since the consultant last saw me. My weight has increased by 5kg. A very good sign. The fitness routine seems to have worked as well. I now have a 28 inch waist, and the belly that was there seems to have moved to my chest! The tan is coming on nicely. In fact, I can't remember the last time I looked this good. It remains to be seen what this week's sputum samples will show. I hope that the consultant comes to see me soon. I feel calm, and for the first time in months I feel really confident that I am winning this battle.

The consultant came to see me about 5.45pm this evening. He said things which buoyed me up even further. It seems the trip to the United States may have paid off after all. In the first instance, he says I look better than I did before he went away. More importantly, he seems to have made up his mind about the criteria for my release. If I achieve three negative sputum smear tests in the next three weeks I can go. He is going to sort out some accommodation that is suitable for me. It looks like I may be out of here soon. The last thing he told me was really amazing: his trip to the US has definitely changed things. So long as I comply with Directly Observed Therapy, attend the clinic at least once a month and remain sputum negative, I will be able to lead a relatively normal life. The only thing I really mustn't do is spend time with immuno-compromised people.

I am frightened. I have become used to living in isolation, and soon I am to be set free. It seems like quite a challenge, and the thought of an open space is very daunting.

TUESDAY 3RD OCTOBER 1995 The weather is pretty dismal: it is raining heavily. I completely missed the summer; I feel so much better when the sun shines. All I have in here is the constant flicker of an overhead fluorescent light. I feel a little depressed; this seems quite usual considering the time (about 5pm). I think this is because most of the people who help me have gone home and have probably forgotten about me - I am just another part of their work.

FRIDAY 6TH OCTOBER 1995 Something has got to give. I'm trying to find the strength from somewhere, but I feel I am scraping the bottom of the barrel. I pace the floor like a caged animal in some old Eastern Bloc zoo. The drains are smelling particularly bad today. The doctors and nurses come and go. All they ever give me is tea and pills. I am sick of being a disease. I want to be a human being again.

SATURDAY 7TH OCTOBER 1995 I woke up and went through the ritual of getting dressed. I opened the blinds; the sun was shining for a change. I would really like to be out there. Instead, I sit here resisting the temptation to watch children's television. There is absolutely nothing to do. I have listened to my CDs a hundred times or more.

MONDAY 9TH OCTOBER 1995 I woke up at about 8am and got showered and dressed. I threw a paper towel in the rubbish bin which, as per usual, was overflowing after the

weekend. I decided to give my room a bit of a tidy. It is hard to keep such a small space tidy when you have so much in it.

I wasn't expecting the consultant to come to see me today, but he appeared anyhow. He told me that the last sputum sample I had given had come back positive. However, it was only borderline positive. Although it was still technically a positive result the consultant seemed flexible about this. I'm not coughing, and the amount of TB bacilli in my sample is so small that the chances of me infecting anyone now must be minuscule.

The consultant has said that as soon as suitable accommodation has been found for me I can go. When he left, I felt a little shocked. It seemed I was going to have my freedom again after all. I am frightened of the idea of rejoining society. My life has become quite surreal in here.

I sat in the corner of the room and cried. I felt near to breaking point. There had been no visits from the psychologist for the last three weeks. My fear turned to frustration to elation and back again. I paced the room once more.

TUESDAY 10TH OCTOBER 1995 One of the doctors came to see me today with a letter from the consultant. It read:

"I thought it wise to set out in writing our advice to you concerning possible discharge. The following instructions will apply for when you only have small amounts of acid-fast bacilli in your sputum.

You should sleep in a single room with the door closed at night, and should spend the majority of your time inside. It is relatively safe for you to go out for short periods assuming you will not be in close contact with anyone for longer than quarter of an hour or so. This means you will not be able, for example, to go to restaurants, clubs, or use public transport. The flat should be properly

ventilated. You will need to comply with daily directly observed therapy and will be advised to attend our out-patients' clinic once monthly. You should have no new social contacts and should not have contact with anyone who is HIV positive or otherwise immuno - compromised. You should also not have any contact with pregnant women or children."

I was elated. It finally seemed like I was getting somewhere. They have told me I can go this Friday. All I need is one more test result. I don't care. It looks as though I am definitely getting out of here, and that's enough for me.

The day passed, and at about 6.30pm one of the nurses came to see me. "I have got some news for you," he said. 'What now?' I thought: I'd become so used to getting one piece of news immediately contradicted by another. He had been talking with the doctor who had received my latest test result from the lab.

My test results had come back negative!

TB TIPS: ISOLATION

■ COPING WITH ISOLATION

During the course of isolation you may lose an appreciation of the passage of time. Every day feels the same as the one before, and it may be difficult to decide what happened when. It can become very confusing. To combat this:

- Make sure that people close to you know where you are!**
- Is there a clock in the room? If not, ask if you can have one,**

or get someone to bring one in. Ideally, try to get a clock that doesn't tick. I found that the incessant ticking of the clock eventually drove me round the bend - I ended up pulling the thing off the wall and smashing it. It never ticked again, but I didn't know what the time was either.

- Try and establish some sort of routine.
- Open your blinds or curtains when you get up and close them when you go to bed. Sitting in a darkened room you may eventually confuse day and night.
- If you are well enough, get up and get dressed.
- If you have a telephone, great! Find out if you are liable for the cost of any calls made. If you don't make any outgoing calls you can still receive incoming calls and it won't cost you anything.
- If there isn't a telephone in your room, mention it to the staff. It is important to be able to communicate with friends and family, and maintain contact with the outside world. The staff should understand and hopefully sort this out. Remember, if you get this organised, there will be a telephone ready for the next occupant of the room.
- If having your own telephone is a real problem, see if there is a payphone you can use. There should be a payphone trolley on the ward which can be brought to your bed. Obviously, this makes receiving incoming calls problematic. Ask the nurses if they can take any messages for you, and give the ward number to your friends.
- You may try rearranging the furniture in your room. This helps

to personalise it for you and may return a certain sense of control.

- If you have a television in your room, try to watch scheduled programmes e.g. The Six O’Clock News. These will act as regular markers, helping to structure your day.
- Most hospitals have someone who comes around selling newspapers and magazines: make sure you are not left out.
- You may feel that you have lost control over many aspects of your life, but you can still exercise some of the rights that we all enjoy. If you are isolated, there will be warning signs on the outer door telling people what to do when they come in. Make one of your own that says: “Please knock before you enter.” It is a strange contradiction of isolation: there is very little privacy. There is nothing worse than drying yourself down after having had a shower, and a domestic decides she wants to clean your room.
- Ask someone to bring some personal effects from home e.g. pictures or posters. This may help to further personalise what might otherwise feel like an austere little cell.
- Keep a diary, draw or do some other activity to make the time pass, creatively. It is good to feel you are achieving something.
- Some isolation rooms have a kettle and a fridge so that the occupant can make their own tea. It’s not nice to have to ask for a cup of tea every time you want one. If you feel well enough, it gives you a little more independence.

- If you are a smoker like me and you are allowed to smoke (if you are in a negative pressure room then they can hardly complain), make sure that you have ample supplies of cigarettes. It is difficult to get through the day with no cigarettes if no one is going to visit and the demon of addiction starts nagging you!
- If you are to be isolated for a while then you are going to need clean clothes. Ask the nurses if they can sort out your washing for you. There are usually facilities for doing this. (Make sure you mark your clothes in some way so that they can be identified. I ended up having a rather charming, but greying pair of women's knickers being handed back.)
- If you have some space in your room, you may feel like doing a little exercise. Ask if you can see the physiotherapist. He or she may be able to offer some equipment and/or advice. I was fortunate enough to find the exercise bike. Isolation compounded by the weight loss due to the TB leads to muscle wasting. Try to keep some muscle tone.
- Ask to see a psychologist regularly if you are having trouble with the combination of isolation and side effects. Frustration, resentment and loss of control are common feelings, and they may be able to help you deal with them.
- Remember, you are undergoing treatment. At times it may seem hard, but a relatively short time of discomfort could ensure a complete return to health.
- Try to make an effort with your personal appearance. It is important for self-esteem and it takes up time.

- Fluorescent lighting gives some people headaches. You should be able to bring in a bedside lamp or other lighting from home. Bulbs that simulate daylight are also available.