

People with AIDS

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Hans was twenty-two. Except for a rather shabby greyish sheet, he lay naked on a double bed. His body was covered with large ugly black sores. I wondered if it was catching.

Earlier that evening I had been in my room, reading. I had been ordained about a year, it was 1984, and I had never even heard the word AIDS, though in fact three years had already gone by since, in Los Angeles, the first signs of a new viral infection had come to light. The telephone had rung, and a man called Carl, with a young voice, had asked if he were speaking to a priest. I had said I was. He had told me that his friend was dying. He himself was not a Catholic but his friend was. He had asked me to visit them.

At that time I was a curate in West London, at the Catholic Church of Our Lady of Victories, Kensington. The Parish takes in the Earls Court area. Earls Court has a large homosexual population, and Hans and Carl were part of that community. I call it 'a community' because, in many ways, that is just what it is. Earls Court has many pubs and places where homosexual men can go, and there is a feeling of support and acceptance among them. In fact, there is something rather 'cliquey' about the place.

Carl, Hans and I did not begin a heated discussion about the rights and wrongs of homosexuality. There were far too many more urgent problems. Carl had given up his job so as to be at home to look after Hans. They had no money, little hope, and Carl was coming to the end of his tether.

It seemed to me that the first thing to do was to make Hans comfortable, so we changed the sheets and gave the flat a general clean-up. Diarrhoea is a real problem for people with AIDS, so a washing machine is essential. I always used rubber gloves but not because Hans had AIDS but because I would anyway. The fear that I felt when I first saw Hans disappeared, once I got down to work. In any case, as soon as you get to know people you begin to see how things really are.

As the days went by we managed to get things sorted out, but a week later Hans died. The funeral was terrific, as funerals go. Lines and lines of young men were there, nearly all in leather jackets, and with short hair-cuts and moustaches. The elderly ladies who usually attended the 12.30 Mass did look a little puzzled at first, I must say, but they were more supportive than I thought they would be. The congregation sang

and sang. A good funeral is better than a bad wedding any day, and that was a good funeral. I think Hans would have been pleased.

Because of a funeral or a wedding a priest sometimes becomes 'known', and I began to visit a number of men and women with HIV and AIDS. I did this in the first place to bring them Communion, but, as most of them were my own age, often we would become friends. It is a hard thing to watch one's friends die, one after another.

In 1988 I became Chaplain at St Mary's Hospital in Paddington. I was responsible for the pastoral care of all patients and staff in the hospital who were Roman Catholics, but one of the distinct features of St Mary's is that it has a number of wards that cater mainly for people with HIV and AIDS.

Writing about the pastoral care of these people, the first thing that has to be stressed is that the disease they are suffering from has very distinct stages, and it is worth recalling these.

The first stage is *Initial HIV Infection* (HIV stands for *Human Immunodeficiency Virus*). Within a few weeks, or even hours, of the virus entering the body, some people experience something which resembles influenza, but people only know that they are 'HIV Positive' if HIV antibodies are found in the blood; there may be a long period of good health, lasting years, during which the disease is dormant.

The second stage is *PGL (Persistent Generalised Lymphadenopathy)*, when there is a general swelling of the lymph nodes or glands, which the patient may not be aware of even if it last a long time.

The third stage is *ARC (AIDS Related Complex)*, when the HIV virus has already done great damage. Patients may now suffer from night sweats, fever, severe malaise, fatigue, lethargy, excessive loss of weight, diarrhoea, skin rash; they are now very ill and need a great deal of care and support.

The fourth stage is *AIDS (Acquired Immunity Deficiency Syndrome)*, when the immune system has collapsed and the person is completely at the mercy of any life-threatening opportunistic infection or tumour.

There is another stage, *AFRAIDS (Acute Fear Regarding AIDs)*, which mainly affects people who are not HIV positive, but this stage is very dangerous for everybody!

It is most important that we use the right words and phrases, for the words that we use in our work can either give hope or destroy it. We should not describe persons as having AIDS when in fact they are HIV Positive; also it is important to speak about 'living with' HIV rather than 'dying of' HIV. Other words to be avoided are 'patient' (many people are trying to live as normal a life as possible) and 'victim'.

This, however, could be said about the pastoral care of all sorts of sick persons. Sometimes people say to me: 'Persons with AIDS shouldn't be treated any differently from anybody else.' What these people are

actually saying is that they believe we are paying too much attention to persons with AIDS and HIV, that too much money is being spent on them. Sometimes there is an undercurrent of feeling that they have got what they deserved.

These critics are right insofar as we all need lots of tender loving care especially when we are dying, but there *is* a difference, in that a whole generation has been hurt badly by the horror of AIDS. We expect sickness and death to come when we are old, but AIDS primarily affects young people, who thought that they had been promised a life of seventy or eighty years and now feel cheated. Far from being tired, like so many of the very aged, they are full of life, full of ideas, of dreams of adventures, of so much to do. And now there is no time. No wonder they feel cheated.

For this reason, the support that the families of these young people can give can be immensely important. I remember a young man whom I will here call 'Stan'. The black marks from Kaposi Sarcoma, a skin cancer, had started to appear on Stan's face. He was very upset at this. His mother put both hands on his face, brought his head down to her height and kissed him on both cheeks. 'Well, I think you are very handsome,' she said, and they both laughed.

It is often the fathers who have the more difficult time, when they find out that their son or daughter is HIV Positive or has AIDS. The feeling of helplessness and hopelessness seems to hit them more. Marriages can be put under a great strain, for often long and frequent stays in hospital are needed. Sitting at the side of a bed, even when doing nothing, is exhausting. Stan's mother and father went through a very difficult time. One day Stan came home. He had until then lived away from home, in a flat on the other side of London. He had tried to remain independent of his parents, but he had begun to feel and to look very ill. It was only then, two years after his blood test, that he told his parents—first his mother, and then she told his father—what was wrong. His father screamed and shouted. But, strange to say (or is it so strange?) the problem was not that his son was HIV Positive, but that he was a homosexual. That was the greater blow to his father.

The second blow came a week later. Stan had to go into hospital, St Mary's, but then decided not to undergo any active treatment. (Remember, people do not 'die of AIDS' but of the illnesses to which the breakdown of their immunity system exposes them.) He decided to let nature take its course, and not allow the hospital to treat even what was a minor illness.

This situation created three problems. In the first place, what should I say to him, what would the Church teach about this? The Church teaches that we need not use extraordinary means to keep someone alive, but what is extraordinary? There is no cure for AIDS, but Stan was suffering from comparatively small things. Nevertheless, combined and left untreated they might kill him.

The second problem was Stan's father. He was convinced that he had rights when it came to his son's health, and he wanted his son treated. He was very upset when it seemed that everybody was ignoring him.

Thirdly, the other patients felt betrayed. They were struggling to stay alive and they felt that Stan had no right to give up. It was a difficult time for everybody, and a lot of oil had to be poured on a lot of troubled water.

Furthermore, Stan did in fact that time make a full recovery through the natural process of his immune system, which was still strong enough to fight the illness.

This case conveys something of the complexity of the pastoral problems that HIV and AIDS can sometimes raise.

We tend to think of HIV and AIDS affecting men, but there are, of course, many women who are HIV Positive or who have AIDS. Recently a woman came into one of the wards set aside mainly for people with AIDS. She was in her fifties, and she came in with her mother. Her husband had died four weeks earlier. It was he who had contracted AIDS in the first place and unknowingly passed it on to her. He had contracted it from contaminated blood in the U.S. I tell you this because I want to try and describe real anger: her eyes were wide, her mouth moving excitedly, her words full of venom and hate. What had I to say? I wanted her to have peace, and peace comes with forgiveness. How could I speak to a woman in this state, with so many reasons to be angry? How could I begin to speak of forgiveness? This was one of those situations where it is necessary to wait before speaking.

The most important lesson I have learned during my time as a chaplain at St Mary's is not to make excuses for God: trying to find a reason for the bad things that happen is not a good idea. Also I never say 'Maybe they'll find a cure.' or 'People live for years.' These are empty words, and not really worth saying.

So what positive things can I say? One can encourage people who are HIV Positive not to give up but, on the contrary, take care of their health. Taking care of one's health can be taken up almost like a new hobby. Many people who are HIV Positive will say that they are now living life as we all should. Taking exercise and eating fresh and good food can certainly help to slow down the virus. Learning how to relax and taking holidays are also helpful. But, above all, and most important, is to learn how to live day by day, for we live until we die.

A group of people especially affected by the HIV virus are intravenous drug users. At St Mary's there is a needle exchange system. Drug users can bring along their 'works' and exchange them for clean equipment. Many people would say this is wrong, and in the U.S. strong arguments are going on about the rights and wrongs of exchange systems. There is controversy even among the users themselves. I once asked a man at the needle exchange why users shared needles. He told me that a good

comparison was drinking on one's own in a pub, as compared to drinking with friends. To share a needle was, he said, to bond friendships and give the whole thing a party feeling.

Of all the people at risk from AIDS I fear for intravenous drug users more than for any other group, especially when I look into their eyes and see the despair there. When heroin addicts need a fix they will do anything to relieve the terrible pressure, even to the extent of sharing a needle with someone who may be infected with the virus. My visits to the needle exchange have always been distressing, there seems so great a gulf between them and me. In my day-dreams I wonder if I should exchange my smart black suit and collar for jeans and a tee shirt, learn their language and try to reach out to them. But whom am I kidding? This is a foolish and naive dream. I am better employed, I believe, trying to be myself.

After a short period as chaplain, as there were times when I felt depressed and empty of any feelings, people told me that I should have a support group, and I agreed. I joined a special support group for workers with people with AIDS. But in the end I realised talking about AIDS and sharing my own experiences was not helping and at times more than I could bear, and so I left. I have thought a lot about precisely what support is needed, not only for myself but for the doctors and nurses, but so far I do not know.

Things have changed a great deal from that first meeting with Hans and Carl in 1984. AIDS has been given much publicity in the media. Many people have come together to do what they can to help others. However, it is still true that many people who are HIV Positive face a great deal of discrimination and even violence. There is still a lot of ignorance and fear. But I think things have changed to some extent. I have heard of many firms dealing with their employees with great kindness and compassion, not to say generosity. All the same, there is still much to be done, much justice to be fought for. We Christians must fight for that justice, and be the compassionate face of Christ to all, in the sure knowledge that man or woman, straight or gay, black or white, saint or sinner, God loves us all.

Sometimes I hear people say that the Church is doing very little for people with HIV or AIDS. I think that partly depends on one's ecclesiology. I believe that we are the Church, you and I. Whenever a member reaches out to another who is sick, then that is the Church reaching out in a truly wonderful way, and many do wish to reach out. In the same way, of course, whenever a member is sick, then the Church is sick and suffering, for although we are many members we are all one body. AIDS is not a homosexual disease, it is a human disease, and what is required is a human and a humane response. The Incarnation is God walking with his own creation. This, then, should be the goal and aim of all who work with, love and care for those who are sick and suffering: to walk with them down a road which is always difficult but not always dark, even if the disease is AIDS.