

ABC of AIDS

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BEING HIV ANTIBODY POSITIVE

I have known for two and a half years that I have human immunodeficiency virus (HIV) disease. My doctor was not unsympathetic when he told me the test result, but I left the clinic feeling cheated. He had shown concern about how I would cope with the emotional, social, and sexual implications, but the essence of the conversation was:

Doctor: "You seem like a coping sort of person. You'll be all right won't you?"

Me: "Yes, I am a coping sort of person, I'll be fine."

None of us wants to appear pathetic in front of our doctor. I wanted to say that I didn't know how I was going to cope, but I sensed that that was not what he wanted to hear.

For a long time I didn't cope very well. I spent a lot of time getting drunk trying to numb an extraordinary pain of loneliness. Two and a half years ago very few people knew that they had HIV. I didn't know anyone else in the same position. I didn't know then, as I do now, that what I was feeling was part of a common, and natural, reaction.

Losing control

Like many people with HIV, I was acutely anxious about my health. If you have AIDS the enemy is there in front of you; you know where you are. If you are HIV antibody positive you don't know where, or when, or whether AIDS is going to strike. In a sense, you have lost control of your body. You don't know what the virus is doing to it. Every subsequent symptom of ill health—a rash, a sore throat—brings a rush of fear.

I am afraid, also, of becoming too ill, too incapacitated, or too demented to take care of myself. It is difficult for people who may be young, single, and accustomed to being independent and self reliant to contemplate the prospect of surrendering control over their wellbeing to other people. There is a fear of becoming dependent on community services and good will because those services and that good will may not be there.

HIV is a cruelly stigmatised disease. It is difficult to tell someone that you have it—even the people you might usually expect to turn to in a crisis. It may seem easier not to confide in anyone rather than risk a fearful or hostile reaction. But if you don't confide in those close to you you may have to put up barriers to maintain the concealment, and those barriers may undermine a hitherto trusting and honest relationship.

Sexual intercourse is one of the most important means of affirming and maintaining a loving relationship. If you are told that you can no longer have that it may seem as though you are going to become a very lonely person indeed. Everybody wants to be loved, but who would want to spend their life with a sexual cripple?

Sex affects the patterns of people's lives in many ways. For young, single people it may determine patterns of social life.

One's lifestyle, sexual and social, is something that one shares with one's immediate community of friends. If you have to change that lifestyle, to protect your own health and the health of other people, you may begin to sense that you are losing your place in that community, losing your sense of belonging and the identity it confers.

Public image of HIV

Patients may put enormous pressure on doctors to tell them what their chances are of developing AIDS. The doctor may say 15% or 36% or 50%, depending on which cohort studies he or she may have read. The message the patient receives is that his chances depend entirely on a statistic: something outside his control. There is therefore no point in doing anything special to promote or protect his health because nothing he does is going to make any difference.

People with HIV disease, and especially people with AIDS, are constantly reminded that they are probably going to die. You turn on the television or open a newspaper and, in the context of an item of AIDS, you will see yourself described in terms which make it clear that, in society's eyes, you are finished.

The relationship between large sections of the media and the public depends on the manipulation of sensation, particularly moral sensation. AIDS has been interpreted as a moral contamination afflicting people who have behaved "immorally" or "deviantly." People with HIV and AIDS have been told that they are responsible for this disease, they have only themselves to blame, they "deserve" it. People with HIV are not immune to those messages. They undermine self esteem and self confidence at a time when those qualities are most needed if one is to come to terms with the psychological and social implications of discovering that one is infected.

Support and anger

Two things saved my self esteem. Late in 1984 the Terrence Higgins Trust set up a support group specifically for people who were HIV antibody positive. For the first time the people in that group, and I was one of them, had a safe environment in which to talk, openly and honestly, about what had happened to them and how they felt about it. It was all right to cry at the things one had lost: relationships, security, freedom to choose how one lived one's life. It was all right to be angry about how society was treating you. It was all right to talk about fear.

Some of us in that first group went on to form the self help group Body Positive, an example of a community of people

infected with HIV helping and supporting each other, offering each other love and compassion, determined to challenge and contradict the notions that HIV was "deserved," a moral contamination, and that people with HIV were "finished."

The second thing that saved my self esteem was anger. Anger at a medical system which allows doctors to do a professional job by reaching a diagnosis, but which equips them with neither the insight to recognise that in giving that diagnosis they may be taking away so much that gives meaning and purpose to life, nor the skill to help their patients find a way to replace that loss. Anger, too, at finding out that doctors and health care workers were as vulnerable as anyone else to irrational fears and could even allow prejudice to undermine their special commitment to caring for the sick.

I was angry mostly at discovering that it could be tantamount to a crime to have a disease. I have been very fortunate. I have not lost a job, my income, my flat, my friends, or the love of my family because I have "the AIDS virus." Others have. It is why people who have HIV are so afraid of losing control over who knows. For me there are few risks in other people knowing. For me concealment is not a satisfactory strategy for coping with the disease. It should not have to be a strategy for anyone. If you have to conceal things

it implies that you are not fully in control of your life. It aggravates that sense of isolation.

Ironically, the quality of my life has improved considerably since the crisis I went through. The reassessment it forced of my values and relationships has brought enormous rewards. I have adapted to my new circumstances. Doctors can make that process of adaptation less painful for their patients by becoming aware of the obstacles that may make it difficult for patients to come to terms, emotionally, socially, and psychologically, with the diagnosis and how patients could and should be helped. For example, it is essential that doctors refer patients to counsellors and agencies able to assess and meet their needs.

It is essential, too, that doctors share with their patients a concept of health where "health" is not defined as longevity. We know that people react to crises somewhere between one extreme of saying, "There is nothing I can do about this; I am the victim of circumstances beyond my control" and the other extreme of saying, "I can be in control of what happens to me, and I can change things for the better through my own actions." Doctors can help patients move towards that determination to achieve a sense of wellbeing through their own actions. In the absence of a cure for HIV, it is possible, with encouragement from one's doctor, to achieve one's own personal and private victories against this disease.

Medicolegal

Consent and the mentally handicapped

CLARE DYER

Does the court have power to consent to an operation on a mentally handicapped adult who cannot give valid consent? That question was left hanging in the air when the House of Lords delivered judgment in the "Jeanette" sterilisation case last April.¹ Sunderland Borough Council made Jeanette a ward of court before her 18th birthday so the court could give its consent under the wardship jurisdiction, which applies only to minors.

Once she reached 18, it was thought, no one, not even the court, would have power to consent. But while the case was progressing through the courts some commentators cast doubt on this interpretation of the law. They suggested that the court retained some residual jurisdiction after 18 to take decisions on behalf of those who were mentally incapable of deciding for themselves, under the ancient common law principle of the state as *parens patriae*.

The point was raised in the House of Lords, but their lordships were unwilling to commit themselves without the benefit of full argument, for which time was too short. For the same reason the power was not argued in two subsequent last minute court applications to sanction abortions on mentally handicapped women. In both these cases the judges did not give consent to the abortion but simply made a declaration that doctors would not be committing an unlawful act in performing the operation.

Now the case of T,² a 19 year old Welsh girl with a mental age of less than 3, has confirmed that the court has no power to consent to operations under the *parens patriae* jurisdiction. T, with an intelligence quotient of less than 30, is doubly incontinent, uncooperative, and destructive and is taking large doses of drugs to control epilepsy. Her pregnancy was discovered at only 11 weeks, so there was time for the point to be fully argued. Mr Justice Wood's judgment confirms that the residual jurisdiction may still exist but there is now no one who can exercise it. The Crown's ancient prerogative rights over "mentally disordered persons" were delegated to the Lord Chancellor under the royal warrant. But the last royal warrant was revoked in 1960, when the Mental Health Act 1959 came into force.

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