

AIDS: A NEW REALM OF BEREAVEMENT

3RD INTERNATIONAL CONFERENCE ON

GRIEF & BEREAVEMENT IN CONTEMPORARY SOCIETY

THE UNIVERSITY OF SYDNEY

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Sydney, Australia, 4 July 1991

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The Hon Justice Michael Kirby AC CMG*

*"That is no country for old men. The young
In one another's arms, birds in the trees
- Those dying generations - at their song,
The salmon-falls, the mackerel-crowded seas,
Fish, flesh, or fowl, commend all summer long
Whatever is begotten, born, and dies.
Caught in that sensual music all neglect
Monuments of unageing intellect."***

AIDS - A GLOBAL PANDEMIC

A month ago I was in Geneva. The occasion was the fourth meeting of the Global Commission on AIDS (GCA) of the World Health Organisation (WHO). The GCA is a body of twenty-five experts, in a number of relevant disciplines, established to advise the Director General of WHO (Dr H Nakajima) on the strategies which should be adopted to combat the spread of this new and unexpected epidemic.

Across the table sat Luc Montagnier of the famed Pasteur Institute in Paris - the quiet French scientist who

First isolated the human immuno-deficiency virus which causes the breakdown of the human immune system which results in AIDS. Closer to me (for we were arranged in alphabetical order) was the United States scientist, Robert Gallo who devised methods for the routine propagation and handling of retroviruses and thereby made possible the achievements of Montagnier. But for the work of these two men, and a few others, we would be looking at the spread of the HIV/AIDS epidemic with an even greater sense of disbelief and horror.¹

Around the table were participants from different disciplines. I was the only lawyer. Medical scientists and epidemiologists predominate. But there is a sprinkling of social scientists, representatives of non-governmental agencies, international bodies with relevant operations and public health experts. We come from all continents. We reflect different creeds and moral positions. We are intended to be a microcosm of humanity, assisting in the struggle of a great challenge to humanity, which now reaches the four corners of the world.

The meeting received some hopeful news on the research being performed for the development of a vaccine to prevent the ravages of HIV, including in people already infected, but symptomless. Fourteen countries are participating in a series of trials to develop a vaccine against HIV. One of the scientific experts (Dr Howard Temin of the United States, himself a Nobel laureate) suggested that the vaccine might be less than ten years off. But ten years is grim news for those already infected and those who support and treat them. No silver bullet for the treatment of HIV or AIDS was

unveiled to the meeting; no simple cure. Indeed, some of the scientific contributions doubted that HIV, in its multiple manifestations, would ever be cured by a simple pill.

For me the most chilling moment came in the reports given to the meeting by Dr Jim Chin, a distinguished United States epidemiologist. His is the task, within WHO, to track this epidemic. He must project the graphs of currently known data in order that the experts in that grey building in Geneva can alert member governments and a watching world about the dimension of the AIDS epidemic, its likely patterns of development and hence the needs for funding and other initiatives to combat its spread.

With the aid of computergraphics, Dr Chin was able to show the current state of the epidemic in each of the continents. In Europe, North America and Australasia the graph of the epidemic which peaked so quickly in the 1980s had begun to level off. The projection suggests a flatter curve. But in Asia, with the input of new statistics from Thailand and India and from the borderlands of Burma, the graph begins to show an alarming upward mobility. So too does the graph for the Caribbean and Latin America. Most tragic of all is the projection of the figures of the infected in Africa. It is sketched vividly in my memory. Yellow boxes which grew and grew: every centimetre of growth representing a collection of human suffering of quite awful proportions. The news from Africa - and particularly from Uganda and Zaïre - is terrible.

According to Dr Chin the general trends just recounted will increase. The world-wide trend is towards that pattern

of HIV distribution which has always been shown in the developing world: heterosexual spread through the general population. The number of children who will be orphaned in Africa - many of them infected perinatally - is alarming. And Dr Chin's statistics on the global level are reinforced by figures presented by Dr Michai Viravaidya of Thailand. From tests performed on young Army conscripts, the penetration of HIV, in part by vectors of the sex industry, to young males and females throughout Thailand is a source of the greatest anxiety.

This, then, is the global epidemic of AIDS caused by HIV. It is exactly ten years since the first paper was published in the United States recounting a strange new phenomenon noticed first amongst young homosexual males in San Francisco.² Initially, this condition was described as GRID (Gay Related Immune Deficiency). The puzzling features of it were kept quiet at first, despite the valiant efforts of a few to raise the alarm. Prestigious medical journals declined articles for a few crucial years upon the grounds that the reports were alarmist, the epidemic affected a narrow group and the features of it were not yet scientifically demonstrated. Sadly, thousands, perhaps millions, will pay the price for this early caution. Now the alarms ring everywhere. All around the world people know of the challenge of AIDS. It is challenge to economies, to health care systems, to overstretched budgets and the medical dollar, to the support systems - to the families, and above all to the individuals who are infected. It is a story with many heroes. In the context of bereavement it is a story which presents special new problems. It behoves civilized

communities to confront these problems directly and to seek to diminish the burden of grief on those who are infected and those who love, support and care for them.

THE FEARFUL PATIENT

Bereavement begins before death. Everyone knows that HIV is a seriously life-threatening condition. It is important, however, to avoid talking of people who are infected as if they are already dead. Most of them are very much alive. For the most part, they live ordinary lives full of routine. They like to be called People Living with AIDS (PLWA). They must not be written off. In concern about vaccines and cures we should be concerned as much for the already infected as for those not yet exposed to that predicament. PLWAs have a great economic, social and individual contribution to make to society. They are found in every walk of life in developed countries such as those of Australasia, Western Europe and North America. They are found everywhere. To the few who still talk of the quarantine option for people infected with HIV it must be said that there is no justification for such a response at least in ordinary cases. Fortunately for humanity, HIV is a fragile virus. It is comparatively difficult to acquire. Its major modes of communication involve blood and sperm. The major means of infection are sexual intercourse and the use of unsterile equipment for intravenous drug injection. Perinatal and neonatal infection of infants is another source. But unprotected sexual activity is the chief vector. Once again nature uses exquisite pleasure (for reasons not yet fully understood) to spread a virus which is usually fatal to the host.

I say usually fatal because this epidemic has not yet been with us long enough for us to trace every pattern of the infection. Some patients live many years, apparently free of health problems. Others come quite quickly to the breakdown of their immune systems. At least the general pattern is by now well established. The person infected becomes mildly ill within a short time of infection. That illness is overcome by the body's vigorous and healthy immune system. Years pass (typically ten or eleven) without symptoms. Comparatively suddenly, there is a breakdown of the immune system. The vital T-lymphocyte cells diminish. The immune system crumbles. The body is rendered vulnerable to a range of usual and unusual assaults which a normal immune system would throw off with comparative ease. HIV turns to ARC (Aids Related Complex). ARC turns to AIDS. It is in this last phase that the patient suffers greatly. In addition to physical ailments, a significant proportion of patients suffer loss of mental acuity, dementia and inability to attend to ordinary activities of life. This process is not inevitable. We do not know whether (and if so why) some of the people infected will throw off the infection or, at least, never fall victim to that crucial final decline in the immune system. There are many curiosities about HIV and AIDS that are not yet fully explored.

Nevertheless, the typical case is now so well documented that the pattern of HIV is established. At least in western countries - and increasingly elsewhere - patients know the pattern. Knowledge of the pattern comes from health care workers, the medical profession, specialist literature and the news media. Patients know the pattern from their

friends. Knowledge that HIV is usually life-threatening; often fatal, follows an established route and results in all too many cases in death is a tremendous burden for those who are infected and those who support them.

Infection and illness have always been with humanity. What is so special about HIV/AIDS? The special features are well established. They include the fact that most of the patients are comparatively young. Most of them are otherwise perfectly healthy. Most would, but for HIV, have gone on to normal life-span. Many of them, at least in western communities, are already alienated. If they are IV drug users they live in a secret world, apart from society because of the criminal sanctions which attach almost everywhere to IV drug use. If they are homosexuals or bisexuals their lives have, since puberty, been partly cut off from their surrounding community. If they are in the sex industry, they are often despised by "respectable" citizens.

All research on bereavement in the context of HIV/AIDS reports the special problem which derives from the sense of shame which many patients experience from having acquired HIV and the sense of despair that this is not a condition which miraculous medicine in the age of heart transplants can cure or prevent. The connection with blood, sex and death presents a metaphor which is vividly etched upon the consciousness of society. If cancer is a predicament causing death which has to be whispered, HIV/AIDS is all too often the condition that dares not speak its name. Yet its name must be spoken if we are to understand its dimension and its toll on fellow human beings on every continent.

The sense of shame about sexual activities - and

particularly homosexual or bisexual orientation - is all too often sourced in religious instruction derived from the teachings of the prophets of the religions of the desert that influence the moral codes of much of the world and of all western countries. Significantly, the gospel of Jesus Christ brings a message of unconditional love, of hope, forgiveness and reconciliation. But the other prophets of Christianity, Judaism and Islam are not so forgiving. They stigmatize sexual activity outside heterosexual marriage. They provide sources for a great burden of guilt about non-marital sexuality. Feelings of guilt cause much individual suffering and distress. In the context of HIV/AIDS it is a principal source of the shame which makes acceptance of illness more difficult for the patient. He or she cannot even readily talk to relatives, friends, neighbours and fellow workers of the condition which is so life-threatening and so intimidating. All too often, the precise nature of an increasingly manifest illness must be hidden from family and friends or dressed up in pseudonyms: cancer is the most common. This provides an added burden for the infected. As well as living with this burden, many of them lose the intimacy of close personal relationships. Unless such relationships are already established before the condition is confirmed, patients feel still further alienated and cut off. Death is not their fear in many cases.³ Frequently, the concern is about pain, the fear of dementia and above all anxiety for the shame which, it is felt, the discovery of infection with HIV will bring to the family, amongst the neighbours, the work colleagues, the friends. Secrets will then out. Even if half-known, they will be

disclosed. The personal intimate world of the individual will be laid bare. The private zone shared with chosen friends will become common property: gossip, rumour, speculation. All of these concerns add cruel burdens to the weight of illness and the perceived threat to the continuance of life itself. Many of these burdens may be traced back to fears about sexual expression. The desert religions have, I regret to say, imposed with their inspiring instruction, cruel messages of deprivation, of selfishness and unforgiveness which stand in stark contrast to the simple message of Jesus, the lessons of Buddhism and the acceptance of human nature in all of its extraordinary variety inherent in most humanist philosophies.

For patients infected with HIV who have been brought up in a religious tradition (even if they have later thrown it aside) a particular difficulty is presented when practitioners of that religion will not reach out to help and support the dying or even those bereaved. Sadly, the papers at international conferences on AIDS are replete with stories of such rejection. They represent a shocking indictment of those who dare to claim a religious and moral a position.⁴

THE BURDEN ON THE HELPERS

Enough of the burden on the individual who discovers that he or she is infected with HIV and knows what that grim news means. That person will go through the well known steps of grieving: anger - disbelief - pretence - rejection - final acceptance and reconciliation to fate.

One of the particular phenomena now being noticed - ten years into this epidemic - is the special burden which

HIV/AIDS places upon those thrown into unexpected contact with people with HIV/AIDS. They are found in every community. In the frontline are the medical and nursing staff who daily attend to the patients: challenged by the inability to provide the quick prescription and the magic cure. This adds a novel stress to health workers which many of them have not been accustomed to enduring. There is a problem in such stress. It may be endured for a time. Ultimately, however, even the most compassionate will need release from such constant, daily burdens. They will need counselling, support and assistance for the grieving process they also go through in the constant loss of patients, many of whom become respected friends. A feeling of helplessness has not been the usual professional companion of the modern health care worker. Armed with fantastic technology and with a thousand drugs on the pharmacist's shelves: vaccines, potions, cures - the feeling of an inability to provide effective treatment takes the health care worker back to earlier times. It also exposes him or her to the fears of those times: fears of self-infection, fears for dependants and co-workers, fears of personal inadequacy in the face of insuperable challenges.

All of these are natural fears. They occur particularly where reports arise of the spread of HIV from health workers to patients and vice-versa. The recent report of a dentist in the United States who allegedly infected a number of his patients has caused considerable alarm in that country.⁵ It is an alarm which must be put in context. The epidemic has been abroad in the United States for more than a decade. It is sometimes estimated that more

than a million people are infected in that country with HIV. Operations and intrusive health procedures have been conducted on such people for the whole of the period of the epidemic. We can take reassurance from the very low figures of health workers infected. Most of the health workers who have reported work-related infections are nursing and operative staff who have suffered frank needlestick and have thereby received substantial quantities of infected blood. This fact provides a reason to avoid undue alarm. It is also a reason to reject the additional unnecessary precautions, tests and intrusions which threaten further to alienate patients with HIV, pushing them unnecessarily away from help and into isolation which is not warranted by the degree of the risk to the health of others which they normally present.

The health professionals in western and other communities have responded with courage to the AIDS crisis. But some of them have lately become overwhelmed by AIDS. One of them wrote recently in the *Washington Post Health Report*. He is a homosexual physician who has been involved with AIDS from the beginning. In his article, he predicted an early retirement:

"I saw my first AIDS patient in 1984. Like so many to come, he was a nice man. When he died a few months later, a little of me died with him. It also made me feel very vulnerable - there was no way to know at the time if I was infected or not...."

Probably the most difficult aspect of treating the patients at the time was the shame so many felt for being HIV-infected.

Then two things happened that destroyed my denial and killed my optimism. Studies began to show that over time the risk of developing AIDS increased, so that by 10 years, more than 50 percent of people had developed the disease and an additional 25 percent had symptoms of

AIDS-related infections. ... This made me feel that no infected person was safe from the virus.

More and more of my patients developed AIDS and died. They taught us many things in medical school, but not how to avoid feeling pain when your patients suffer....

Yet most of my patients appropriately retain their denial in order to cope. But inside, I cringe when they ask me to check their cholesterol levels, as though it's going to matter 20 years from now. One patient on AZT asked if I thought he should quit his job, give up his health insurance and start a risky business on his own. I had to point out that there was a good chance he would be sick in a year or two and therefore should not give up his health insurance.

I have stopped accepting new HIV patients. And I know that other physicians, both gay and non-gay, care for many more HIV-infected patients than I have. I consider them all heroes. But some have quit. And others, infected themselves, have died. None of us picked AIDS as a specialty - we just happened to be at the right (wrong?) place at the right time.

I feel I have done my share. Although I have tested negative for HIV and my physical health is good, AIDS consumes me 24 hours a day. So for my emotional health, I just want the pain and suffering to end, both for my patients and for myself.

Even as I write this, I hope my patients don't see it. I do not want to add to their burden; they're in enough pain, and I don't want to feel as though they have to bear any of mine."

Then there are the chaplains and religious supporters for PWAs and their families. There are many fine supporters who are religious and dedicated. In Sydney, the Sisters of Charity at St Vincent's Hospital have, from the beginning of the epidemic in Australia, offered unquestioning help and professional treatment to their patients. They have not found the time or the necessity to judge them or their lives. A number of priests and ministers of religion too,

have ministered to the sick and dying - and to the bereaved - in ways that command admiration and gratitude. Such people exist in every community. Their lives have a special quality because of their spiritual commitment.

One hospital chaplain recorded his first encounter with AIDS in October 1985 at the St Michael's Hospital, Toronto:

"I had been directed to the closed door of a patient's room from behind which I heard a man sobbing. The nurse told me that this man had just learned of his AIDS diagnosis and that he was alone. Would I go and see him?"

Not knowing how to say no, and aware of the growing fear and anxiety within me, I entered his room. Against one wall, to my surprise, stood a nurse and a doctor, in silence. On the bed a man rocking back and forth, sobbing, clutching a pillow. I stood with the doctor and nurse in silent fear. After about ten minutes of this vigil and out of a blind need to act, I crossed the room, took away the man's pillow and substituted my shoulder. At that point, the doctor and nurse left. For the next hour we rocked back and forth, together, as he continued to quietly sob. Finally he found the inner strength to call his family and friends to tell them he had AIDS, was dying and was homosexual. Almost two hours later his friends arrived and I then left.⁷

At the time this chaplain extended his unconditional love, he was deeply frightened. He did not then know about the process of transmission of HIV/AIDS. But, as he explained, HIV/AIDS compelled him to:

"Journey to the most intimate levels of who and what I am; as a man, a Christian and chaplain. Confusion and pain have been, and continue to be, integral parts of that journey. And I realise I have only just begun."⁸

AIDS has also placed new stress upon funeral workers and the religious people and counsellors who work in conjunction with them. An Anglican priest described how, one

evening, he was on duty at a funeral home and two young men walked in the front door:

"They were well dressed, good looking and in their late twenties. 'We would like to make funeral arrangements', announced Darrell. 'Has a death occurred?' I enquired. 'No', he responded, 'it's for me'. I showed them into an office and proceeded to prearrange his funeral. 'I may as well tell you, I have AIDS. What I want to know is, will you accept my body, what will you do for us and what will it cost?' Fortunately the firm that I was working for had established a very positive policy for dealing with people who had died from AIDS-related illnesses and I was able to offer him a full traditional funeral. [Darrell] was quite animated as we spoke and his happy, carefree faade betrayed an underlying fear of what the future held. Dan, his lover, wasn't so animated. He sat back in the chair, quietly listened and occasionally wiped a tear from his eye. Clearly he was more realistic about what they were doing that night."

According to the priest, Darrell, countering his grief, was simply seeking to think of other things. He was talking as if death were simply a change of home - from his ordinary home to a funeral home. This was his way to cope with AIDS.

I have now attended too many funerals of school friends, professional colleagues and personal acquaintances who have died of AIDS. Like all funerals, they represent a catharsis and a ceremony of transition. Unfortunately, they all too frequently bring together groups who, in life, are indelibly separated. Most incomprehensively of all, that separation is frequently the result of religious instruction or misinstruction and the attacks on people and groups at risk of HIV infection by fellow citizens expressing their views in the misunderstood name of religion.

"Fundamentalists have been notoriously outspoken

against gays, as has been the Roman Catholic Church. The fundamentalists have declared that gays are reaping what they have sown and that the disease is a judgment from God. In spite of this, many gays have a deep spirituality that has not been stifled by the church's indifference and in some cases active opposition.¹⁰

A typical funeral tale can be told:

"I will never forget Sal and Grant. I met them at the funeral home one day when they came to pay their respects to a friend who had died. Sal had AIDS and asked me to prearrange his funeral. When I asked him who would conduct the funeral, he said 'Well my family is Roman Catholic, but I don't want a Catholic priest conducting my funeral!' I was already studying for the ministry so I invited him and his lover Grant to the church where I had a student assistant. I began to visit him regularly and one day about three months before he died, he said 'I know I don't have long and I'm not sure I'm ready to die'. He asked me to call the priest from our Anglican parish to hear his confession, which I did for him. From that point on, he seemed to be more at peace. He stopped talking about all the things he still wanted to do. I began to take him Communion on a regular basis. One day I went in and he was especially weak. After I gave him Communion, he lay back on his pillow, nodded 'Yes', smiled and closed his eyes. He died two days later.

Before he died he told his lover that if his family wanted, their parish priest could take part in the service. Our church was full for Sal's service, with the Roman Catholic priest assisting our priest. When it was over, his lover Grant said 'Why couldn't it have been this way when Sal was alive?'.¹¹

In New South Wales, and possibly other places, particular and unnecessary indignities are imposed upon people dying of AIDS and those grieving for their loss. By regulation, bodies must be wrapped in double polythene bags, heat sealed, with the words "Infectious Disease - Handle With Care" placed on the body in colours of prescribed colour and height.¹² Access to the body for viewing (required or

conventional in some ethnic communities in particular) is denied. Good laws and policies on HIV/AIDS must be based upon sound scientific data. There is no justification for basing such regulations upon fear, myth or public health rules framed for earlier times and different health conditions. Amongst all the indignities and burdens of HIV/AIDS, we do not need, by the law or by our attitudes, to heap further loads upon those already heavily afflicted. The regulation I refer to was the product of trade union insistence during the early phase of this epidemic. The union, unwilling to take the risk accepted by the chaplain just described, insisted upon double polythene bags. With our present knowledge of the condition, it is time that this regulation was repealed or disallowed.

*"Once out of nature I shall never take
My bodily form from any natural thing,
But such a form as Grecian goldsmiths make
Of hammered gold and golden enamelling
To keep a drowsy Emperor awake;
Or set upon a golden bough to sing
To lords and ladies of Byzantium
Of what is past, or passing, or to come."***

THE OLD FAMILY AND THE NEW FAMILY

Particular problems of reconciliation in bereavement for the death of a patient from AIDS-related complications arise from the need to bring together the patient's old and new families at and after the time of death. We should spare a thought for the "old family" - the biological parents, siblings, grandparents and others. Often they have to cope not only with the news of grave illness and approaching death but with discovery (sometimes the confirmation of a family secret) of the sexual orientation, drug use or other

activities of the patient. Sadly, and especially in rural communities, the product of this discovery can lead to the shunning of the patient: adding to the burden of a terminal illness. But usually, a family rallies in a crisis when priorities are suddenly straightened out. Of course, this depends upon particular cases. Especially in minority communities particularly such acceptance is not universal. In the United States, the Afro-American and Hispanic communities are sometimes more intolerant of homosexuality or drug-taking than the caucasian society has come to be.

The discovery that the dying patient has a circle of unknown friends, many of them obviously gay or defiant drug users, will put added pressures upon conventional families. They may sometimes reproach themselves and ask "where did we go wrong?". The impending loss adds to the urgency and insistence of these questions. There can even be conflict between the claims of the parents for the terminal care of their infected child and the comforting desire of the patient to remain in the familiar company of a lover, partner or friends. It is important here to help the old family to understand that, quite apart from sexual relationships (which may have ceased) the personal communion and companionship of partners is as much a feature of homosexual as of heterosexual relationships. Disturbing such communion at a time of grave illness can do positive harm to the spiritual peace of the patient.

Within the homosexual communities of western countries a whole network of support has grown up since GRID was first identified a decade ago. The "buddy" system provides support for those who are alone to confront their terminal

condition. A "buddy" is provided to do the necessary shopping and the things a really sick patient cannot do. In a number of places in the United States the Gay Men's Health Crisis Centre has afforded specialist assistance to people with HIV and AIDS in an environment and community which is supportive and comforting to them.¹⁴ Similar help has been given by the London Lighthouse¹⁵ and by caring institutions and organisations in Canada¹⁶ and in Australia.¹⁷

The self-same problem of "burnout" to which I have referred in the context of health care workers exists in this network of friends and supporters. Some of those who are helping are themselves infected. Their commitment is reinforced by attendance at repeated funerals. With death they go through their own crisis in advance. A special phenomenon which has been noted in the context of AIDS is the profound personal difficulties faced by those who experience chronic mourning.¹⁸ In the summer of 1987 a panel of 624 men in New York named an average of 6.2 men of their acquaintance who had died of AIDS. Only 5% of them reported no losses whatever due to AIDS. At least one loss was reported by 44% of the sample during one or two of the years preceding. More than 50% reported at least one loss during each of the three or more consecutive years. Looking at the percentage of men who have been bereaved, the picture reverses. About 51% of the men had not yet lost a close friend or lover. Forty-four percent had been bereaved in the two years preceding. Another 5% had been bereaved for three or more consecutive years. These bereaved men were more likely to be living in the midst of a gay community.¹⁹

They often felt themselves forced by their sexual orientation and community alienation to find support in friends with a similar life's experience. Yet that very feature of their lives is now reinforcing the experience of repeated bereavement. In the journals they read, the hotels they attend, at home and in their social lives they are surrounded and constantly reminded of the appalling toll which HIV/AIDS has brought upon their communities. This is a distinguishing feature of the epidemic. Most people of the age of these patients may have to face, at about the same time, the death of one or possibly two parents. But confronting daily and over a period of years the death of close friends, lovers and partners adds an element of intolerable pain to the repeated burdens of bereavement.

A natural human response to bereavement is an effort to identify the cause that can be blamed. This is why in courts we often see attempts to nail down the tortfeasor responsible for a death whether in a motor vehicle accident, negligent medical treatment or other wrongful death litigation.²⁰ It is why, for deaths in official custody court cases²¹ and Royal Commissions²² search out the reasons for death and seek to identify the causes and, where appropriate, apportion responsibility and blame. It is why legislation has been enacted to provide compensation for the victims of crime.²³ It is a very normal thing for the family of someone who has died before time to seek some degree of solace and understanding of their grief by identifying those responsible. But who is responsible for the infection of a family member with HIV? In some cases a lover or a husband, or some identifiable

person, can be found. In most cases, however, the source is quite unknown. The search for the perpetrator leads all too often to self-criticism and even self-condemnation. An overwhelming feeling of guilt is a frequent response. Such feelings reinforce the complex responses that exist in our community to sexual expression.

Many of those infected with HIV stand in a different position to other people suffering from a fatal condition. They cannot readily talk about their condition to the whole circle of their friends, even though it may be a matter which daily obsesses them. The law and society do not provide the support systems to reinforce committed personal relationships that provide strength in such a testing time of life. Even in matters so mundane as industrial entitlements to bereavement leave, there is generally no legal entitlement to leave in the case of a partner or close friend. Such entitlements are typically restricted to spouses, parents and children.²⁴ Because of the changing nature of relationships today, this consideration presents fewer difficulties than once it did. But the burden of the partner who must carry a daily grief in silence from family and friends is one largely inflicted by the attitudes of our society and partly by attitudes of individuals themselves. We must overcome these attitudes before a just society is created.

To the stresses to which I have referred must now be added the outbreak of violence which has been noted in recent years against members of the homosexual community. It spans continents. Young people, insufficiently instructed by parents and their religion in the message of reconciliation,

exhibit their individual fears by violent attacks upon people they suspect of being gay. Such people become a symbol of the danger of AIDS to newly discovered sexuality. Murders and serious assaults upon young men in Sydney have led to prosecutions, convictions and punishment. But all too often the victim does not complain; the perpetrator cannot be identified; if identified, the evidence is not available to secure conviction; the jury may acquit. The cycle of violence is repeated. Fortunately, with the support of special police units and efforts in schools, attempts are being made to educate young people in the total unacceptability of this form of violence. Yet the wave of violence, borne of fear, continues.

And the violence is not only physical. There is verbal violence as well. It is found in the most unexpected of places. On 3 July 1991 it was given voice in the Legislative Council of the Parliament of Tasmania. The Council rejected the HIV/AIDS Prevention Measures Bill 1990. Amongst many other measures designed to combat the spread of HIV/AIDS, the Bill proposed the removal of the provisions of the Tasmanian Criminal Code which make "carnal knowledge of any person against the order of nature" a serious and punishable crime. Such provisions were removed in South Australia and Victoria more than a decade ago. One by one the other States of Australia have removed such provisions from their statute books. But not Tasmania. According to press reports, a Launceston member of the Council, Mr George Brookes said that instead of decriminalisation, the law should be tightened to encourage homosexuals to "take the flight back north" to States of Australia where such acts were not an offence:

*"Don't let them sully our State with their evil activities."*²⁵

Then another member of the Council urged logic and that the arguments of the opponents to reform smacked of the Old Testament instruction that homosexuals should be put to death, another Council member, Mr Hugh Hiscutt interjected:

"Not a bad idea either."

The former Liberal Attorney General for Tasmania, Mr John Bennett, was reported as saying:

*"I want Tasmania to show the way to that island off our North Coast. I won't do anything to legalise sodomy, no matter which State does."*²⁶

Responding to the rejection of the measure, the convener of the Tasmanian Gay and Lesbian Rights Group, Mr Rodney Croome, suggested that it proved that on such issues in Tasmania politics was governed by hysteria and ruled by hatred:

*"Regardless of what they have to say in there, we will continue to campaign for decriminalisation."*²⁷

So the messages of hatred, contempt and verbal violence against fellow citizens are not confined to ignorant and fearful youths in the anonymity of a metropolis. They reach even to the elected representatives of the people in a democratic Parliament. They reinforce the impediments to the spreading of educational messages essential for the practical containment of the HIV/AIDS epidemic. But they also add to the burdens of bereavement: for the dying, for their partners and friends and for their loving family. May those

responsible for such messages of hatred be forgiven for the pain they cause.

In the *Book of Common Prayer*, the Collect for Ash Wednesday contains a message that should be sent to these people and indeed to all people - and to us all:

*"Accept our Repentance, Lord, for wrongs we have done; for the blindness to human need and suffering; our indifference to injustice and cruelty; for all false judgments; for uncharitable thoughts toward our neighbours; and for our prejudice and contempt toward those who differ from us."*²⁸

FOOTNOTES

Commissioner of the World Health Organisation, Global Commission on AIDS. Trustee of the AIDS Trust of Australia. Commissioner of the International Commission of Jurists. Personal views.

W B Yeats, "Sailing to Byzantium" in *W B Yeats, Collected Poems*, Macmillan, London, 1982, 216-7.

1. See Dominique Lapierre, *Beyond Love*, Century, 1991. See *ibid*, 113 ff.
2. The *New England Journal of Medicine*, the most prestigious medical journal in the United States did not judge it "expedient" to publish submitted articles. See Lapierre, *ibid* 116. Possibly the first article published by a responsible medical journal was by *Morbidity and Mortality Weekly Report*, June 5 1981. See now "The HIV/AIDS Epidemic: The First 10 Years", *Morbidity and Mortality Weekly Report* June 7 1991, vol 40 No 22, 357. See also Lapierre, 85. Hence the reference to

ten years. For likely developments see A Carr, "The HIV/AIDS epidemic: the next ten years" in (1991) 5 *National AIDS Bulletin* (Aust) #6, 9.

C A Wagner, "Opening Windows" in (1988) 4:4 *Journal of Palliative Care* 9, 10. Hereafter JPC. See also P W A Mansell, "AIDS: Home, Ambulatory and Palliative Care" in JPC, *ibid* 33.

J K Saynor, "Existential and Spiritual Concerns of People with AIDS" in JPC, *ibid*, 61, 63. Cf J Reid, "AIDS, Chastity and Compassion" in *Southern Cross*, (Journal of the Anglican Church in Australia), July 1991, 9.

See "Transmission of the Human Immuno-Deficiency Virus in the Health Care Setting - Time for Action" in *New England Journal of Medicine*, 23 May 1991, 1504. See also J Elford and A Cockeroff, "Compulsory HIV antibody testing, universal precautions and the perceived risk if HIV: A survey among medical students and consultant staff at a London teaching hospital" (1991) 3 *AIDS Care* 151; M W Ross and E C Hunter "Dimensions, content and validation of the fear of AIDS schedule in health professionals" (1991) 3 *AIDS Care* 175.

6. N R Schram, "Overwhelmed by AIDS" in *The Washington Post Weekly Journal of Medicine*, 18 June 1991, 14. See also L Bennett and Ors in "Quantitative analysis of burnout and its associated factors in AIDS nursing" in (1991) 3 *AIDS Care* 181.

7. D N Graydon, "AIDS: Observations of a Hospital Chaplain" in JPC, *ibid*, 66.

8. *Ibid*.

9. J. K. Saynor, above, 62.
10. *Ibid*, 63.
11. *Id*, 64.
12. Public Health (Funeral Industry) Regulation 21(2) NSW, 1987; cf *Public Health (Control of Diseases) Act*, United Kingdom, 1984. See discussion M D Kirby, "AIDS & Law", (1989) 118 *Daedalus*, 101.
13. S L Librach, "Whose in Control? What's in a Family?" in JPC, 11.
14. L Katoff and R Dunne, "Supporting People with AIDS: The Gay Men's Health Crisis Model" in JPC, 88. See also M A Fraser and J Hesse, "AIDS: Home Care and Hospice in San Francisco: A Model for Compassionate Care" in JPC *ibid*, 116.
15. S I Mansfield, "The London Lighthouse" in JPC, *ibid*, 100.
16. D C H Ley, "The Casey House Model" in JPC, *ibid*, 111.
17. See J J Guinan and Ors, "Stressors and rewards of being an AIDS emotional-support volunteer: a scale for use by care-givers for people with AIDS" (1991) *AIDS Care*, 137. The article describes the work of the Ankali Project in Sydney. "Ankali" is an Australian Aboriginal word for "friend".
18. L Dean, W A Hall and J L Martin, "Chronic and Intermittent AIDS - Related Bereavement in a Panel of Homosexual Men in New York City" in JPC, *ibid*, 54, 55.
19. *Loc cit*.
20. P C Rosenblatt, "Grief and Involvement in Wrongful

- Death Litigation" in 7 *Law and Human Behaviour*, 351, (1983).
21. See J A Hambridge, "The Grief Process in Those Admitted to Regional Secure Units Following Homicide", 35 *J Forensic Sciences*, 1149. See *Cekan v Haines*, (1990) 21 NSWLR 296 (CA).
 22. Royal Commission on Aboriginal Deaths in Custody, *Report*, 1991, AGPS, Canberra.
 23. "Bereavement Damages - Too Little, Too Late" in (1990) 140 *New Law Journal*, 1678.
 24. See eg discussion "Formal Entitlements to Bereavement Leave" in [1988] *Industrial Relations Review and Report* 412.
 25. Reported in *Sydney Morning Herald* 4 July 1991, 1.
 26. *Ibid.*
 27. *Loc cit.*
 28. See also *St Matthew's Gospel* 9:35-36.