

# Caroline Chisholm Centre for Health Ethics

BULLETIN

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SUMMER

1996

## From the Director

As we enjoy Victoria's mild summer it is time for the second issue of the our **Bulletin**. It will be published quarterly, with annual subscriptions coinciding with the financial year, running from July to June. We will normally publish two numbers from August to November and two from February to June.

We plan on making our Bulletin reader friendly, but still solid in content on issues pertaining to health ethics. Efforts will be made to keep our ethical theory in touch with health care practice. Articles will usually range from 500 to 1500 words, but not exceeding 2000 words. Articles will not normally have end notes. The Centre will, however, prepare a number of kits on a variety of topics and issues relating to health ethics. These kits will have longer articles and will be documented. A list of the kits available and their prices may be obtained from the secretary of the Centre.

The Centre is organising two major events this year. The first is a Special Lecture - **Making a Critical Difference - "The Care of the Dying"**. This will be an outstanding audio-visual presentation by two palliative care physicians from Brisbane on 28 February 1996. See the invitation on page 7 of this Bulletin for details. Later in the year on 3 May we will hold our first major one day Conference on **"Ethics and Resource Allocation in Health Care"**. For details see page 10.

We welcomed Deirdre Fetherstonhaugh to the Centre's staff as a research officer in October 1995. She is a nurse of many years experience with specialist qualifications in renal nursing, before graduating from La Trobe Uni-

versity with a B.A. in Social Science and an M.A. in Health Studies. Her thesis was on resource allocation in health care. We hope Deirdre will enjoy working at the Centre.

At the end of the year we farewelled Sr Mary Stainsby RSM, a research officer at the Centre from March 1995. Her substantial articles have appeared in the first two issues of the Bulletin and will also be in the next issue. Her vast experience, practical knowledge and advice have been invaluable during the transition from St. Vincent's Bioethics Centre to our own new Centre. We are very grateful to Sr Mary for her great contribution and her cheerful presence among us. ✚

*Norman Ford SDB*

*Rev Norman Ford, SDB, Director, with Officers of the Board of Management,  
Dr David Campbell, Deputy Chairperson, Mr Livio Antolovich, Treasurer*

## FEATURING

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# Further Comments on Victoria's *Infertility Treatment Act 1995* and Related Ethical and Moral Issues

*This article concludes a discussion on this Act which was commenced in the first number of the Bulletin. It deals with the monitoring of infertility treatment, the Infertility Treatment Authority, its advisory committee, the availability of information in cases of donor gametes, counselling, informed consent and the position of the*

## Monitoring of Infertility Treatment Procedures

The **monitoring** and control of infertility procedures are important issues. The Act provides both for a licensing system and for the use of criminal penalties. A too ready recourse to criminal sanctions may even be counterproductive. Sympathy in such personally sensitive issues can tend towards an offender thus making a conviction hard to establish. Probably the most effective means, which seems to be the intention of the Act, is to rely mainly on a licensing system, backed up by criminal sanction, whereby a practitioner who goes beyond the conditions of his or her licence (i.e. in carrying out unauthorised procedures or research) loses the licence and according to the nature and degree of the lapse may be liable also to a criminal penalty.

A professional carrying out a procedure or research (or responsible for such) and the institute or premises where these procedures or research are carried out must be licensed, with provision being made for the first time for the licensing of day centres. This dual level of licence conditions (of practitioner and premises) will enable an institute to continue functioning when a breach of licence conditions has been the sole responsibility of a researcher and the institute could not be expected to be aware of it.

The effective monitoring of licence conditions will depend much on the quality of the decisions made by the members of the Authority. In the enforcement of regulations it needs to be kept in mind there are limits beyond which the law cannot go, and

morally should not go, in the control of people's private lives.

The provisions set out for the control of surrogacy are similar to those in

*“There are limits beyond which the law should not go in the control of people's private lives”*

the 1984 Act, making it a criminal offence to provide or accept payment, or become involved in advertising a surrogacy, either on behalf of oneself or of another, and surrogacy agreements have no standing in law. It is not permitted to use IVF (in-vitro fertilisation) for surrogacy. This is probably as far as the law can go.

The **Infertility Treatment Authority**, set up to monitor the Act (Clauses 121-139), is a corporate body which will take over much of the work formerly referred to the Minister or to the Department of Health and Community Services or to the Committee. The Authority's duties include the issuing of licences, the approval of doctors and keeping of the Central Register. Its seven members, nominated by the Minister, are chosen to give representation to a diversity of expertise and experience. The Authority is to base its decisions on input and advice received from the Committee.

This Committee, the **Standing Review and Advisory Committee on Infertility [SRACI]**, will solicit input from the community on infertility matters, advise the Minister and advise the Authority regarding the approval or rejection of applications for research. Its role is one of checks and balances.

The Committee is to consist of up to 14 members drawn from groups of diverse expertise and will include for the first time (ie. absent from the

1984 Act), people born as a result of fertilisation procedures and participants in programs for infertility treatments (**Clauses 140-148**).

## Identifying Information about Donors

A most significant feature of the Act - and again in line with placing the interests of children first - is to enable a person born of a donor treatment procedure, on reaching the age of 18, to receive **identifying information about the donor**. This was not possible previously. This clause (**Clause 79**) should go a long way in assisting those born of donor procedures to develop a sense of identity about themselves and their origins. The children of those born of donor treatment may likewise apply for and receive such information.

Those born of donor treatment procedures before this clause takes effect will not be eligible to receive identifying information as the new provisions will not operate retrospectively. Some regret has been expressed over this. In response, previous donors claim they were assured at the time their anonymity would be respected and request this lawful assurance be upheld.

Others draw attention to the law governing adopted children, which law has worked retrospectively in enabling adopted children to receive identifying information about their natural parents. Notwithstanding that Clause 79 of the 1995 Act will not work retrospectively, there are nevertheless expectations that those in the donor categories will consent, if requested, to identifying information about them being given to those born as a result of their donations.

The Act allows for this.

In further provisions parents may request non-identifying and identifying information on their children and a donor may request similar information about someone born as a result of that person's donation and about the parents. In these instances to receive identifying information consent is required, i.e. of the donor, or of the parents, or of the one concerned if he/she has reached the age of 18 (Clauses 75-78). In each instance counselling is to be made available, and there are clauses governing confidentiality and appropriate exemptions from the Freedom of Information Act 1982.

Information on those born of donor treatment is to be held by the Authority in a Donor Treatment Procedure Information Register. This Register is not part of the Central Register and is in addition to the information on infertility treatment procedures to be kept by each licensed centre. The accurate keeping of records is a crucial issue in the administration of the Act. Yet, in setting up procedures to do this care needs to be taken that infertility treatment centres are not weighed down by administrative overload.

## Information Counselling and Consent

The Act, and justly so, places much emphasis on providing for information, counselling and consent (Clauses 9-19). Those presenting for treatment procedures as well as donors must be given information on the implications of their intended participation. Information needs to include procedural matters and indicators a couple's probability for success. The overall success rate for IVF is approximately 10% and for GIFT approximately 20%; yet in each instance there are several factors operative in producing a result, i.e. a woman's age, each partner's health status, general well-being or some genetic trait.

Infertility counselling needs to be more broadly based than opening up discernment options on medical treatments. Sometimes an inability to conceive may not be amenable to a treatment procedure, but may be associated with some other factor.

There is increasing evidence, for example, of links between environmental hazards and infertility, i.e. from chemicals used in fertilisers or from industrial wastes. These factors are associated particularly with male infertility. In taking steps to reduce these environmental hazards some infertility problems can be lessened.

Other couples fail to conceive not because of any physical condition but due to some psychogenic (psychological or emotional) factor, such as a couple's inability to relate

***“Infertility counselling needs to be more broadly based than opening up discernment options on medical treatments”***

easily with each other, previous trauma, a miscarriage or an abortion. Others feel constrained by social or family pressures to bear a child while all the while feeling unready to assume parental responsibility. If these emotional and social factors are causing the problem then it is these that need to be addressed.

Counselling can go further still by opening up alternative responses to infertility. Among these are adoption or fostering a child, working with children in a child-care setting, teaching or nursing, or taking up some quite different career, i.e. through the arts, science or sport. An extension of the 1984 Act is in providing for an infertile couple to receive follow-up counselling.

At the same time however the Act could go further than it does in setting up counselling at this broadly based level and in having its services available independently of an infertility treatment centre.

## Consent

The Act sets out strict procedures regarding consent. A couple intending to participate in a treatment procedure and a donor (in the case of donor treatment) need to receive adequate information and counselling in order for their consent to be an informed consent. Consent must be in writing, consent forms must be duly lodged and consent may be withdrawn. The obtaining of consent applies equally for research, where consent must be obtained from those who produced a gamete, zygote or embryo to be used in research.

Consent for research can be given only in relation to a specific research proposal and the research must be carried out in accordance with the conditions set out in the consent form. In the case of donors, whether for a treatment procedure or for research, the consent of a current spouse of a donor is required (Clauses 9. 12-19, 27-32, 34-38).

In establishing such strict conditions regarding consent, couples intending to take part in treatment procedures and donors are encouraged by the Act to consider the consequences and obligations that may be inherent in their decision. The seriousness of this aspect is clearly established in the clause enabling a person born of donor treatment, on reaching the age of 18, to receive identifying information on the donor.

Throughout history there have been tales of people yearning and spending many agonising years searching for their genetic origins, for signs of a relative or for information on some ancestor whose traits they bear. It is ironic that on the one hand much praise is given to advances in genetic screening whereby a genetic abnormality likely to be passed on in the parents' sperm or oocytes can be detected, and on the other hand there are some people, including senior infertility practitioners, who advocate the practice of anonymous donors because in this way parents can implant their own imprint on the child they bear. Biologically, this is not possible.

Genetically, there are no anonymous

donors. A decision to become a donor, or to bear a child of donor treatment is more than a medical decision. It is a serious ethical and moral decision and one not to be taken lightly.

***“Genetically, there are no anonymous donors”***

There are some who - quite apart from their religious affiliations and from their experiences in working with children - speak out against not only donor treatment and surrogacy but against almost all forms of assisted conception, claiming these procedures are detrimental to the integrity of the women who participate in them and to the rights of the child. Children born of these treatments, it is said, can come to be looked on as a commodity. This may be an extreme view, but the possibilities for excess in having recourse to infertility treatments need to be kept in mind.

**The Position of the Catholic Church**

The Catholic Church holds that a medical technology, i.e. in infertility treatments, is being rightly used when it assists in a human reproductive process and this technology is in error when it interferes with this natural process.

The Church is not in favour of IVF because in this procedure the child is not the fruit of the marital act as fertilisation takes place outside the woman's body. The Church is opposed to destructive research from fertilisation onwards.

In GIFT (Gamete Intra-Fallopian Tube Transfer) previously collected eggs and sperm are placed in a woman's fallopian tube for fertilisation which takes place as in a natural process within the woman's body. The Church has spoken neither in favour nor against GIFT. This pro-

***“The Church is not in favour of IVF because the child is not the fruit of the marital act”***

gram is available within some Catholic hospitals.

Catholic agencies and hospitals share in providing some infertility services, i.e. in infertility counselling, in the GIFT program and in associated ministries to infertile couples. In doing so they uphold the intention of the Act and also of the Church in placing the interests of children first.

**Conclusion**

Infertile couples are entitled to support and assistance in their desire to have children. The Infertility Treatment Act 1995 states this among its guiding principles yet ranks it fourth in order of priority.

Of paramount importance, and the first principle, is to ensure the welfare and interests of children born or to be born of treatment procedures; secondly, is to preserve and protect human life; and thirdly, is to consider the interests of the family.

These three form the basis on which decisions to assist infertile couples

***“First ensure the welfare and interests of children”***

are to be made; and this can be done incidentally and in formal ways. Incidentally infertile couples are supported by community attitudes of acceptance of them, by avoiding giving them an impression that infertility is an illness or a disease, or that a cou-

***“Secondly, protect human life; thirdly, consider the interests of the family”***

ple must have a child. Assistance is given in formal ways by providing access to treatment procedures as provided for under the Act and discussed in this article.

The success of the Act depends much on adherence to its guiding

principles - by the Authority, the Committee, by practitioners in treatment procedures and research and by the community. In its implementation there is a need to ensure that the licensing and legal enforcement provisions are appropriate and that hospitals and associated centres are not overburdened by administrative formalities.

For each of us there is more than one avenue in reaching towards self-fulfilment, more than one way of supporting others in striving towards their self-fulfilment, more than one way by which the interests of children can be held paramount and by which infertile couples can receive our support and assistance. ✚

*Mary C Stainsby, RSM,  
B.A. (Hons.), B. Theol.,  
M.Ed. Admin., Ph.D., MACE*

**IMPORTANT NOTICE**

Subscribers to St Vincent's Bio-ethics Newsletter are reminded subscriptions for this Bulletin run from July to June each financial year. The first two numbers of this Bulletin has been sent to them *gratis*. To receive further copies of the Bulletin it is necessary to send their names and addresses together with the \$20.00 Subscription fee to the Centre, 7th Floor, 166 Gipps St., East Melbourne Vic 3002. Subscribers who have already paid this Centre directly may ignore this notice.

# Euthanasia - Practical Issues for Nurses

*This article approaches euthanasia from the perspective of nurses rather than from the moral view point*

These reflections arise from the recently published results of a replication study, (Aranda & O'Connor, Australian Nurses Journal Aug 1995) ascertaining nurses attitudes to euthanasia. The original study was undertaken in 1992 by Dr Kuhse and Professor Singer from the Monash Centre for Human Bio-ethics, which surveyed a random group of nurses. This more recent study surveyed a specific group of oncology and palliative care nurses to gain insight into the opinions of nurses who worked with the dying on a daily basis. The survey was not altered, but asked nurses to provide some added written comments and it is from this data that most of these reflections are drawn.

The issues under discussion are those that concern nurses who work with the terminally ill; however, they are also issues applicable to the nursing profession as a whole.

## Symptom Management

In relation to pain and symptom management, medical science has increased our knowledge considerably in recent years. As well, there is an increased acceptance in the community of the holistic approach to patients and their symptom management.

*“There is less need to say to the dying - there is nothing more we can do for you”*

Even though there are a very few whose symptoms will be unable to be controlled there is less need to say to the dying - "there is nothing more we can do for you" - because there is almost always something that can increase comfort. The expertise of *palliative care* goes a long way before it is exhausted, but because it

respects the whole person, it may not entirely remove all symptoms.

## Use of morphine

A specific issue of concern in the recent study of nurses was the apparent confusion about the use and actions of morphine. Nurses cited situations where in the giving of large doses of morphine they thought they had killed the patient.

There was surprisingly little understanding exhibited about the difference between a narcotic tolerant patient (which most patients with a terminal illness are), for whom large doses of morphine would most likely not sedate or kill, and a narcotically naive person, who would most certainly be killed with comparatively small doses of morphine. This is a major concern to the researchers, given that the respondents were nurses who worked with the terminally ill. And if this is the case with this group of nurses, how bad is it generally?

## Death as a Foreseen Side-Effect

If the death occurs as a result of the administration of a drug, it is a side-effect rather than a direct result, because hastening death is a price worth paying for the relief of pain. Where there is no evidence to the contrary, the nurse has patient comfort and pain relief at heart. It is not the fact that the side-effect is unwanted that makes it permissible; rather the total package of consequences including unwanted side-effects is morally preferable to the alternative. The consequentialists would argue that the principle of double effect is a negation of acceptance of responsibility for one's actions. i.e: no matter what the inten-

tion in the action, the end point is the same - death - and therefore the intention is morally irrelevant.

**Intention is in fact** very important in this debate and a negation of its importance is a negation of all the advances in care of the dying. We need to view the context and see that the care given at this time is at the end of a continuum of care motivated by a philosophy that seeks to provide comfort and symptom control.

*“Palliative care is not euthanasia and to argue this way is misleading and unjust”*

Palliative care is not euthanasia and to argue this way is misleading, inaccurate and unjust in the anxiety it creates in those for whom care is provided.

Whereas euthanasia is a **deliberate** act with the **intent** of causing death, administering an analgesic within the context of palliative care is a deliberate act with the intention of relieving suffering. Situations that involve the intention to cause death should be dealt with separately from other situations where there is no such intention. Calling all these situations "euthanasia" confuses the issues.

## Comfort of Palliative Care

Palliative care is a specialty of nursing. It assists the dying person and their loved ones to address a range of issues and options at the end of their life - one of these may be euthanasia. The vast majority of people will choose to struggle on with life. Many who request death do so from a lack of information about what can be done for them, or more simply, poor care. A feeling of hopelessness can lead to a request

for euthanasia. Palliative care provides a broad view of hope: not just hoping for a cure, but smaller, achievable, "mini-hopes" - getting out in the garden, going for a drive - and this hope must never be removed.

The cause of euthanasia may be inadvertently advanced by nurses who are not expert in pain and symptom management, particularly in caring for the terminally ill. Who after all, could be blamed for preferring death over agonising pain? Failure to have up to date knowledge in this area, borders on neglect. Access to expert care of distressing symptoms, including pain and psychological distress, must be fully addressed before the issue of terminating a life.

## Confusion on Euthanasia

From the study, there was concern related to the use of language and definitions of euthanasia. Many of the respondents in the study displayed confusion about what constituted an act of euthanasia, elucidating certain interventions or non interventions as being euthanasia, when clearly we felt they were not.

Definitions of euthanasia are frequently shaped, often inadvertently and subtly, by the moral stances people have already adopted on the issue. When you read about this issue, or hear people talking, those in favour of euthanasia, speak of "a dignified death", "a merciful end", or helping to end a "life of intolerable pain and suffering", as though that was their domain.

*“Euthanasia is neither suicide nor assisted suicide”*

Could any compassionate people possibly be against that? And those against euthanasia may use words like "killing" or "medical homicide" or "destruction of life". And who could possibly be in favour of that? So if definitions and interpretations are loaded, how can we really be sure what we are talking about? Euthanasia is neither suicide nor as-

sisted suicide. It is also not withholding or discontinuing life prolonging treatment and is different from pain and symptom control.

Most of what is called passive eutha-

*“If the intention to cause death is not present, the action is not euthanasia.”*

anasia is kindly common sense withdrawal of burdensome treatments, in the context of the person approaching an inevitable death. Nurses need to be professionally confident about these distinctions, because as already stated, if the intention to cause the death is not present, the action is not euthanasia.

## Autonomy not the Only Right

In relation to the current debate, those who champion autonomous rights of the terminally ill to claim their time of death sell themselves short on rights. Nurses are concerned about the protection of the many rights of the terminally ill and their loved ones - the right to have informed choices about care, the right to receive expert care, the right to withdraw from treatment, the right to have one's symptoms controlled, the right to die in the place of one's choice and many others. In seeking to honour individual rights it must be remembered that people do not die in isolation. To argue from such an individualistic point of view without consideration of its implications for the community fails to take into account the total interrelated social picture.

## Accompany the Dying

Nursing has always been about **accompanying the dying person to death** and a request for euthanasia should not mean abandonment to a lonely journey. From recent research, nurses' response to a request for assistance in ending a patient's life depends very much on the context in which the request is made. It

seems to be difficult for a nurse to express an opinion one way or another, without isolating the patient. And perhaps this is not a situation calling for a conscientious objection action of "opting out" - rather it calls for a hanging in, in supporting patients as they explore their request in a holistic way. If nurses will not do this for the patient - who will? - the doctor often doesn't have time.

## Legalising Euthanasia

Talk of the **introduction of legislation** for euthanasia in Victoria, may be unwarranted, because unlike other States, Victoria has had a lengthy inquiry into care of the dying in the **Inquiry into Options for Dying with Dignity 1986 - 87**. The possibility of legislation for euthanasia was part of the Inquiry and considered to be not necessary at the time. What was of greater concern was the level of confusion in the community regarding the current legal situation.

It is the opinion of the researchers who carried out the survey that the situation has changed little. People need to be educated about their rights to refuse medical treatment as they exist under the law at present. Enormous energy went into the **Inquiry into Options for Dying with Dignity**. The result showed little knowledge of, or use of, Victoria's Medical Treatment Act, by the general community and health professionals. Why do we need new laws?

The respondents in our study did not consider that requests for euthanasia

*“There would be concern about changing the law for everyone for the sake of the few who make the request”*

were frequent or enduring in their experiences of care for the dying. Of note was the complex and transient nature of requests, which to the researchers indicated the danger of not exploring the situation at length with the patient and the family. Active euthanasia was portrayed as the last resort for a small minority of patients.

Hence, from this study there would be concern about changing the law for everyone for the sake of the few who make the request.

## Euthanasia a Complex Issue

Qualitative comments received in the replication study reinforced the view that a nurse is unlikely to be acting alone in the withdrawal of medical treatment, or in following a request for assistance in euthanasia. The idea that a patient makes a request and the nurse responds ignores the context of both hospitalisation and the person's life. In the study the respondents were more likely to support law reform to allow doctors to practise euthanasia, than to be directly involved themselves. This issue is of grave concern to nurses in the way that it impinges on the autonomy of practice. From viewing the legislation in the Northern Territory, it seems unclear as to the kind

of legal protection offered to nurses who involve themselves in acts of euthanasia.

## Action for nurses

Nurses need to be involved in this debate in several crucial ways:

- ◆ to participate in public awareness raising of palliative care and of people's rights to refuse treatment under Victoria's Medical Treatment Act;
- ◆ to become skilled and expert in palliative care and to lobby for more adequate palliative care resources;
- ◆ to represent the nursing voice in our role as accompanists on the journey to death, and not simply to be seen as for or against euthanasia.

## Conclusion

There is much work to be under-

taken in understanding nurses' unique experience of euthanasia requests from a contextual view, and not only from a biomedical view, in order to illustrate the complexities of euthanasia as a social response to suffering. The conclusion of the researchers from the study and the accompanying qualitative data, was that euthanasia is not perceived as a black and white issue for all nurses. There is room for further research to assist nurses to clarify the importance of the contextual issues in relation to euthanasia and requests for it ✦

*Margaret O'Connor, R.N., M.N.,  
B. Theol., F.R.C.N.A.  
Director*

*Caritas Christi and Order of Malta  
Hospice Home Care Service Inc.*

## *Invitation to a Public Lecture*

### **MAKING A CRITICAL DIFFERENCE "THE CARE OF THE DYING"**

Dr Ross Baillie and Dr Marguerite Robertson  
Mt. Olivet Hospice/Homecare, Brisbane

Two palliative care physicians will explore some of our deepest responses to the suffering of the dying, through the use of art, literature, music and clinical biography.

Wednesday 28 February 1996

5.00 - 6.00 pm

LECTURE THEATRE  
MERCY HOSPITAL FOR WOMEN

## **Caroline Chisholm Centre for Health Ethics**

7th Floor, 166 Gipps Street  
EAST MELBOURNE VIC 3002

Tel (03) 9270 2681 Fax (03) 9270 2682

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**Director/Editor:**  
Rev. Norman Ford SDB STL PhD

**Research Officer:**  
Deirdre Fetherstonhaugh  
Dip. App. Sc., P.G. Cert. (Renal Nurs.) B.A.  
(Soc. Sc.) M.A. (Health Studies)

**Layout:**  
Ms Sylvie Skonietzky

# HIV / AIDS and Euthanasia

*Far more attention could be drawn to the multi-faceted nuances of HIV/AIDS and the way these affect a person with the virus, one's family and friends. This article discusses these more personalised aspects and in doing so will consider AIDS and euthanasia.*

## HIV/AIDS: an Immune Deficiency with many Characteristics

A feature of HIV (the virus that in its final stages can lead to AIDS) is that each instance of a related illness is distinctive in itself. A person with a weakened immune system due to the virus can be very sick for example with pneumonia for several weeks, unable to breathe without artificial ventilation almost to the point of death. Then he or she can get better and enjoy several months perhaps years of reasonable health, interspersed at times with bouts of fever, diarrhoea, meningitis, pneumonia or skin cancers (Kaposi's sarcoma).

*An immune deficiency* leaves a person susceptible to any number of infections but is not in itself a continuing illness or a "disease" such as cancer or Alzheimer's. With these other potentially life-threatening conditions a person's progress is more or less in a linear direction from good health to ill health, culminating in a terminal outcome, whereas with HIV the progress is more intermittent with a person's health oscillating between a number of highs and lows in wellness and illness outcomes prior to a terminal AIDS illness - which may or may not develop.

The precariousness in the development of HIV brings both hope and intense uncertainty. No cure has yet been found for the virus and anyone with it keeps querying, "By this time next year will I still have the energy to keep working? How am I going to survive financially"?

The losses associated with HIV are

extensive. There is the loss of control over one's life, the envisaged gradual losses of strenuous sports participation, of long-term career prospects and of other life hopes. There are emotional losses associated with disclosure as former friends, perhaps relatives, may give the covert message, "We are just too busy to be associated with you any more!"

An HIV+ person can experience a devastating loss of self confidence and self-image. Brian expressed his feelings, "I was always so careful about my appearance. My clothes used to be the best and I paid the best prices, too; I never bought anything at K-Mart. And here I am, all pale and with no semblance of my former self. I am on drugs just to keep up my existence and yet it is only a shadow of what I once was". Anyone associated with HIV/AIDS lives with death. Philip lamented that, "Within a year I have buried 65

***"Anyone associated with HIV/AIDS lives with death"***

of my friends. A distraught father, even after his son's funeral, honestly felt he could not risk letting his business associates know the true cause of his son's illness, so deeply had he experienced their prejudicial attitudes.

In another instance, in a remote Victorian country town, the family expectations of local rejection on

***"Family expectations of local rejection on bringing their son home to die were not fulfilled"***

bringing their son home to die were not fulfilled and they experienced instead a wonderful warmth and acceptance from their community.

These multiple HIV/AIDS associated apprehensions and losses need to be taken into account.

## How many People have the Virus?

Throughout Australia, cumulative to March 1995 there have been recorded, 18,989 cases of HIV infection (15,970 male, 906 female\*), 5,883 cases of AIDS (5,651 male, 214 female\*), and 4,196 deaths from AIDS (4,038 male, 144 female\*) [\*Totals include those whose sex was recorded as transsexual or was not recorded]. The exposure categories include: 80.7% male homosexual and bisexual contact, 3% male homosexual/bisexual contact and intravenous drug use (ID), 7.3% heterosexual contact, 1.6% haemophilia / coagulation disorder, 1.6% receipt of blood/tissue, 0.1% (nine people) health care setting and 0.9% children. (**Australian HIV Surveillance Report**, Vol 11, No 3, July 1995). HIV/AIDS then has affected men, women and children.

## What stages do HIV/AIDS ill people go through?

The image an HIV/AIDS person wishes to project and the image the family wishes to project of him or her can be strongly at variance and each is likely to go through different stages in coming to grips with the virus. A family often learns their son has AIDS at the same time they find out he is homosexual, with perhaps his "lover" having already died of AIDS. In these instances mutual anguish can intensify already overwrought feelings of fear, shame, dependency or guilt. Quite apart from these negative expectations innate reactions of denial and anger



are common (among the HIV+ person and family). Bargaining is another familiar response in one's efforts to cope, for example, "If I can fight this virus I'll do ten hours voluntary work each week, or, if the test results are wrong and I'm not HIV+ I'll completely change my life style, or, if my son gets better I'll reform my gambling habits". In the absence of personalised support systems bouts of deep depression almost inevitably follow.

Some HIV+ people contemplate suicide. Research has shown suicidal thoughts are more likely to occur soon after diagnosis rather than later on when a person's condition may be full blown AIDS. Another study found that thoughts about wishing to die and of euthanasia were for the most part context specific and occurred almost exclusively during times of serious illness, severe pain or bereavement.

It is during these stages that a sick person's sense of isolation and the experience of having no one to turn to can be felt most keenly. There are some who wish to talk of suicide

***"Research has shown suicidal thoughts are more likely to occur soon after diagno-***

or euthanasia simply to test out a carer or counsellor. Then having aired their concerns, receiving feedback they are being *listened to* and taken seriously they come to feel better about themselves, not so angry and decide they can go on living with AIDS. Another study showed that while anger was evident, hopelessness was not, with some counsellors finding high levels of psychological health independent of a person's AIDS related status.

A number of HIV+ people experience a sub-cortical dementia (which is to be distinguished from the cortical dementia found in Alzheimer's). Sub-cortical dementia affects brain structures important in the regulation of mood and behaviour and shows itself in apathy, a mental slowness, the

avoidance of complex tasks, or in a mania such as hypoactivity, euphoria, grandiose delusions, irritability, a reduced need for sleep, an impaired social judgement or a lack of insight. Dementia needs to be distinguished from depression, which is evident in a person's depressed mood, low self-esteem or irrational guilt. Each out-of-character behaviour warrants a suitable alleviating response.

### **Threats, Depression and the Immune System**

Other research has drawn attention to what has been described as an interdependent relationship between the central nervous system (CNS, hypothalamus-pituitary-adrenal axis) and the immune system, each system being analogous in discriminating between the self and the non-self and in protecting the self against intrusions of the non-self.

Intrusions can come from physically related interferences (infections) and also from perceived threats, that is those *perceived* in the negative messages received from others.

One study reported that 35 chronically depressed HIV+ patients had steeper declines in CD4 cell percentages (a relatively high CD4 cell count is needed to overcome infection) over two years than 70 non-depressed HIV+ men whose cases were used in comparison. HIV de-

***"Intrusions can come from physically related interferences"***

pression, according to this study, can be assuaged by the acquisition of coping skills, thus enabling these people to restore control over their lives.

### **HIV/AIDS People Face the Reality of Death**

Yet for each person with AIDS - and for the family - there is intense suffering and there is no escaping that death is a reality. For a man in

his twenties to be talking about his funeral is an amazing thing in itself. These people want *someone to be with them* in a way that is more than a physical presence. There may be pangs of guilt and anguish to be worked through at the thought of the pain this AIDS illness has brought to loved ones.

It means so much to ill people to pre-

***"These people want someone to be with them in a way that is more than a physical presence"***

pare for their death in a loving, caring atmosphere. Those who have worked with AIDS patients tell how important to them is the preparation for their funeral. No detail is too small to be attended to and the service must be ready and printed well beforehand. It will include no doubt mention by name of those who have given their support, messages of love and affection for those who cannot be here - or who for one reason or another have chosen not to come to the funeral.

An AIDS ill person is likely to be meticulous in making a will. A chaplain mentioned how touched she was by the attention given to, *who is to look after the dog, who is to get the budgie, or who is to receive the books, and the favourite CDs*. The settling of an estate can give rise to sensitive family issues not easily resolved, for example when a dying person sees obligations not shared by the family. In these instances it may be preferable for the sick person and the family/others involved to have independent, but complementary counselling and support. This is, moreover, a time for rebuilding broken confidences and trust, a time rich in opportunities for reconciliation and appreciation of each other. These are processes that cannot be hurried.

### **Euthanasia is the not Answer**

Much has been written of late about

euthanasia, including proposals that euthanasia would provide a suitable *way out*, an easy death and a release from pain for people with AIDS. Yet euthanasia is not the answer. Euthanasia has a number of shortcomings in that the practice:

- a) omits to resolve non-medically related factors;
- b) diverts attention from medically related factors such as alleviation, hospice and palliative care;
- c) diverts attention from providing funding for improved treatment procedures and research for a cure;
- d) and gives no guide as to timing.

Euthanasia fails to resolve non-medically related factors and much of the anguish associated with AIDS is not medically related. The pain of suffering is more than physical pain and pain alone is rarely a reason for anyone requesting euthanasia. Suffering is greater than pain. Suffering is personal and requires a person-centred response which reaches out to the different facets of a person's life that are hurting. What is called for is a revival of lost hopes, a healing of grievances, a spiritual acceptance, reconciliation within oneself and peace with loved ones.

Euthanasia diverts attention from medically related factors such as searching for more effective ways of

alleviating physical pain. It is difficult to sustain a sense of direction in opposite ways at the same time or to focus simultaneously on two opposing solutions. In concentrating on how or when to end a person's life one's attention is geared towards **termination** and turned away from improving the services that are available, including better hospice and palliative care facilities.

Euthanasia diverts attention from providing funding for improved treatments and research for a cure. Why spend millions of taxpayers dollars on research for improved HIV/AIDS treatments and a cure when this money could be saved by having recourse to a speedy termination of life through euthanasia?

*“Euthanasia diverts attention  
from searching for more  
effective ways of alleviating  
physical pain ”*

Thus, euthanasia can seem attractive to policy-makers in health-care, particularly in our financially constrained political climate. Furthermore, as Dr Nell Muirden, Director of Palliative Care, Peter MacCallum Cancer Institute remarked, by allowing some people the right to choose (euthanasia), you would force on everyone the obligation to make a choice.

Euthanasia gives no guide as to timing. It has been noted a person with an AIDS related illness can be at the point of death, with doctors predicting less than a day to live and then get better and enjoy reasonable health for some time. The prospect of euthanasia gives a person no indication of whether to go early or late, or to *hang in there* hoping for a cure. This is not to say that a person is obliged to use all medical means available. Each person has a legal and a moral right to refuse treatment, and to opt for the withdrawal of treatment that is burdensome. The refusal of such treatment can be indicative of respect for human dignity and is to be distinguished from a deliberate termination of a person's life which is disrespectful to human and moral worth. †

*Mary C Stainsby, RSM,  
B.A. (Hons.), B. Theol.,  
M.Ed. Admin., Ph.D., MACE*

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# Medical Confidentiality and its Limits

*In the wake of recent media debates this article discusses when should a doctor tell.*

While the general duty of doctors not to disclose confidential patient information without permission remains intact, the Australian Medical Association has recently amended its Code of Ethics to admit some rare exceptions. These may arise where "the health of others is at risk" or if "required by order of a court to breach patient confidentiality". This change is welcome, but it has taken some years for medical authorities to recognise its need. It responds to perceptions of a community whose social conscience is developed.

People are morally bound to care for their health. Frequently they are unable to do so unaided. The community needs experts to provide this valuable service. Doctors, including psychiatrists and other health care professionals are available for consultation. This may require them to undergo physical examination and to reveal intimate details about their bodies or lives. This personal information is made available in order to receive medical advice, medication or treatment on the understanding it will not be unduly divulged.

## Doctor-Patient Confidentiality Essential

The need for doctor-patient confidentiality highlights an aspect of privacy required by our personal dignity. The undue disclosure of patient information is embarrassing and an offensive invasion of a person's privacy. People simply do not go to a doctor who has a reputation of disclosing confidential patient information.

The provision of health care pertains to the common

***“The undue disclosure of patient information is embarrassing and an invasion of privacy”***

good. It absolutely requires the community's trust in doctors to respect confidential patient information obtained during medical consultations. Little wonder there has always been a strong presumption in favour of strict confidentiality for patients' medical histories.

## Community and Limits of Medical Confidentiality

With the growing sense of the community's social responsibilities in recent years the absolute character of this obligation has been questioned. The common good of the community that normally prohibits the disclosure of confidential patient information, may, in certain circumstances, require discreet disclosure to protect the same common good from serious harm. It would be unethical to protect a patient's confidence if this were to

contribute to a serious injustice for an individual or the community. Limits to medical confidentiality arise because a doctor has a specific and prior duty of care and protection for the health of the community **before** entering into any implicit contract of confidentiality with a patient.

A doctor may not undertake an obligation that conflicts

***“A doctor may not undertake an obligation that conflicts with a prior duty”***

with a prior duty to prevent the unjust infliction of harm to the health of others. Doctors are recognised by the State as medical practitioners who are registered with the Medical Board to serve and promote the health of their patients as members of families and of the community. They are legally required to inform public health officials of all cases of notifiable infectious diseases.

The community expects doctors to have an eye to the public interest and not to be exclusively concerned with

***“Community sanctioned criteria for disclosure would need to be established”***

their own patients. To allay fears of irresponsible breaches of privacy or of doctors being rashly sued in the courts, community sanctioned criteria for the disclosure of confidential patient information to relevant individuals and/or authorities would need to be established and published. Discussions involving the community and doctors would help determine the sort of cases in which absolute professional confidentiality would not apply.

## Lawyers and Priests

Medical confidentiality should not be confused with the stricter confidentiality in the lawyer-client relationship. It is in the general interest of the community that a client should be able to tell a legal adviser everything relevant to the matter for which advice is sought. To engender this confidence in the community, whatever is said to one's legal adviser, directly relating to the issues for which advice is sought, is privileged. The community's confidence in the administration of justice according to law would be eroded if defence lawyers could be compelled to divulge to prosecutors incriminating evidence obtained from their clients.

The priest-penitent confidentiality for the forgiveness of sins is of a different nature. It is absolute because the duty to confess sins to a priest acting in the person of Christ arises from a divine precept, not simply a human need to talk about one's sins with a professional counsellor. The priest in this case exercises a ministry of

religion which transcends purely temporal bounds. As God never reveals what we confess to Him in our hearts, the priest cannot do so because he is a party to God's transcendent mystery.

## Medical Confidentiality and the Law

All other things being equal, patient confidentiality would not be morally binding if, as a last resort, disclosure to relevant persons was required to prevent the unjust infliction of harm of a criminal nature in the community. This ethical duty of discreet disclosure arises regardless of any eventual legal requirement.

In practice, legislation may be needed to require all doctors to comply with this ethical obligation and to

*“Legislation may be needed to require all doctors to comply with this ethical obligation”*

guarantee them legal immunity. In the absence of legislation some irresponsible persons might seek out doctors willing to maintain absolute confidentiality, regardless of any serious harmful consequences to the community. It is sad to reflect that it was recently necessary for the Victorian Parliament to legislate to require mandatory reporting by doctors and other professionals who had reasonable grounds to believe a child was at risk of suffering significant harm from physical or sexual abuse.

Doctor-patient confidentiality must be maintained to the degree required for the community to retain its trust in doctors. A sign that a particular disclosure may be justified is to be found in the answer to this question: Would the community's trust in doctors be undermined if it were known doctors would disclose, as a last resort, confidential patient information to prevent serious harm to the well-being of an individual or the community?

## Examples of Limits to Doctors' Confidentiality

There could be cases of patients whose serious medical condition, including a weak heart, deteriorating neurological co-ordination, poor eyesight, mental illness or drug addiction and which posed a clear threat of serious harm to an individual or the community in view of their occupation or continuing risky behaviour. Normally a doctor should first warn a competent, but uncooperative, patient that discreet disclosure was necessary in the circumstances to prevent serious harm to the health of others before making any disclosure.

Think of the case of a doctor who finds out that a pilot is no longer medically fit to fly an aircraft. The pilot might be reluctant to admit the seriousness of his/her condition, perhaps subconsciously influenced by the need to maintain the level of one's current income to meet

payments for some months. The appropriate authorities should be informed once the diagnosis was confirmed to prevent risk of an air disaster. The same would apply to drivers of trains, buses or even motor cars, air traffic controllers and crane operators etc. A doctor through unjustifiable silence may not allow a risk of serious harm to be inflicted on the community.

There is a general duty to keep confidential a patient's HIV positive status because there is no risk of danger to others from a responsible HIV infected person who avoids risky behaviour. If, however, there were good

*“There is a general duty to keep confidential a patient's HIV positive status”*

reasons for believing an uninfected non-consenting spouse or sexual partner was at risk of being unjustly infected, there would be a duty to disclose the relevant information to the appropriate person or authorities.

## Conclusion

The community expects doctors to report to the relevant persons cases where the risk of harm to the community or an individual is serious. There could be no reasonable objection to this. The trust of the community as a whole in the confidence of the medical profession would not suffer any loss if, in extremely rare circumstances, a doctor were to disclose a patient's confidential information to advise the authorities of a **continuing risk** of serious harm or abuse to an individual or the community. It is not a matter of doctors taking on the role of police officers but of responsible medical practitioners being true to their profession.

In the final analysis it is a question of assessing the balance of benefits and harms to the common good of the community caused by disclosure of, or failure to disclose, confidential patient information. The common good requires the presumption of absolute doctor-patient confidentiality unless disclosure was necessary in a

*“It is a question of assessing the balance of benefits and harms to the common good caused by disclosure of confidential patient information”*

particular case to prevent injustice or serious harm of a criminal nature to an individual or the community. Medical confidentiality exists for the community, not the community for medical confidentiality.

*Norman Ford SDB*