Caroline Chisholm Centre for Health Ethics

BULLETIN

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From the Director

Our Centre was pleased that the Australian Senate had the resolve to withdraw from Australian territories the power to make laws permitting any form of intentional killing known as euthanasia. We congratulate Mr Kevin Andrews MP for the political leadership shown by his courage and determination in seeing that his private member's Bill passed through both houses of Parliament. There is, however, no time for complacency. School and community education campaigns should continue on how best to handle our national challenge to support our citizens who feel lonely or experience pain and suffering as death approaches. It is to be hoped the politicians who spoke so eloquently against euthanasia will be equally forthright in supporting adequate funding for palliative care throughout Australia.

It is sad to learn how prevalent abortion is from the recently published Information Paper on Termination of Pregnancy in Australia: "Abortion is ... a very common experience, affecting at least one third of all Australian women and the majority of families." It also found that contraceptive failure is the usual reason given why abortions are sought. Unborn human life is cheap when the community as a whole permits it to be erased as a mistake. A failure to appreciate the value of human life at its early and final stages coupled with an undue exaltation of autonomy are common to both abortion and euthanasia platforms. Moralising alone will not improve the situation. More reflection is needed on the unique meaning and destiny of God's gift of human life.

Earlier this month the Centre organised a one day Conference for teachers in Catholic schools on ethical aspects of treatment decisions at the end of life. We may repeat this Conference once more for teachers, especially for those in Independent and Government schools later this year.

Our Centre's two new thoroughly researched resource kits on **Health Care Resources** & **Surrogacy** are now available for $20. They will be useful for tertiary and VCE students.

An invoice is enclosed, for prompt payment, with this Bulletin for renewal of subscriptions for Volume 3, from July 1997 to June 1998.

Tracey Scott recently married Mark Phelan. It was a wonderful wedding and we wish them every happiness. ✣

Norman Ford SDB

*"Through the Mission and Values of the Sisters of Charity Health Services, care at **Caritas Christi Hospice** ensures that all patients live until they die."*

FEATURING

Euthanasia: a Clinical Perspective

In this article Professor John Zalcberg explains why both clinicians and proponents of euthanasia share a common objective of preventing or reducing human suffering but differ strongly on legalising euthanasia .

The euthanasia debate around Australia (as well as the rest of the world) continues to gather momentum. In a world first, three patients have legally and very publicly undergone euthanasia in the Northern Territory (NT). The Andrews Bill, withdrawing the right of the NT to legalise euthanasia, has been approved in the House of Representatives but has yet to pass the Senate.* An editorial in *The Sunday Age* newspaper (1997) has called for the legislation of euthanasia in Victoria. The Uniting Church appears to have split from related organisations opposed to euthanasia (Pitt 1997), and in the US, the Federal Court is about to consider whether State based laws preventing euthanasia infringe the constitutional rights of individuals.

Understandably, the nature of this issue has involved a diverse group of people and organisations. While some have other agendas (individual rights, etc.), in the main, the majority in favour of the legislation of euthanasia wish to reduce or prevent unnecessary human suffering. Although it is of some concern that a few of those supporting this solution to the problem of suffering appear to have been influenced by tragic personal experiences, their objective remains a noble one — an objective to which many of us have devoted our entire professional lives. Why is it then, that so many clinicians working with patients so afflicted are opposed to the legislation of euthanasia, when we share the same objective? Undoubtedly, some of this opposition has a religious and/or moral basis, but considerable opposition comes from professional clinical groups or individuals involved in the day to day care of such patients. In the area of cancer, for example, (to which this issue is the most pertinent, at least on a numerical basis), various clinicians (Mullen 1995; Buchanan 1995) and organisations including the Australian Association of Hospice and Palliative Care (AAHPC) are opposed to such legislation.

From my perspective, the clinical issues are two-fold. After years of caring for patients with advanced cancer, it has become apparent that the vast majority of such patients wish to live, not in suffering, but nevertheless they cling to life, sometimes in circumstances that those of us in good health may well consider unbearable. In fact, most requests for euthanasia have invariably represented 'cries for help', either from suffering patients, but as often from family members who are experiencing difficulties in coping with illness. This 'cry for help' often disappears when careful, skilled attention is paid to the real issues at hand, often not solely the physical distress of the patient. In this context, euthanasia represents an illogical solution to a superficial assessment of the clinical issues. (What does the patient really want/mean? what is his/her state of mind? which problems are solvable and how are they interrelated? what are the family dynamics? etc. etc. are questions rarely considered by those advocating such legislation, particularly when lacking appropriate clinical experience).

Solutions such as these may appear to trivialise the complexity of the suffering experienced by some patients and/or their families and certainly will not succeed in every instance. But to succeed at all, they require clinicians coordinating teams with relevant expertise and experience. Expertise in the diagnosis and management of difficult pain syndromes or other complex physical symptoms, expertise in the psychiatric evaluation and counselling of patients and their families, highly developed communication skills, time ..., time to sit, to empathise, to support, to hold hands. That such teams are not always widely accessible, particularly outside large metropolitan centres, is an immediate but potentially correctable problem.

But of greater concern is the fact that many patients are not referred to, or cared for, by such teams because of an attitude expressed at some time or other by all of us — "If I can't fix the problem, it can't be fixed". This culture of medical omnipotence, based on a genuine desire to help in the context of limited training and/or experience and the often unrealistic expectations of the community, such that some doctors fail to accept or appreciate the limitations of their own knowledge, is much less common now than in the past. But in an environment in which the legislation of euthanasia is being considered, it should set alarm bells ringing. This concern is not about establishing adequate mechanisms to enforce legislation that may be abused (such as has occurred (Hendin 1994) in the Netherlands), but rather, represents a fundamental limitation inherent in a medical system which will undoubtedly, ultimately be charged with the responsibility for the practice of euthanasia.

So what of the suffering patients — must they continue to endure endlessly? Not if it is humanly possible to do otherwise. In appreciating the instinctive wish to live and the knowledge that the majority of patients who actually request euthanasia do so because of uncontrolled pain, depression or lack of family support (Chochinov et al. 1995), a variety of meaningful interventions can be considered. Solutions involving specific therapies such as outlined in the article by Hooper et al. (1997), or teams of appropriately qualified experts as discussed previously, can begin to address apparently intractable problems.

As I have suggested previously (Zalcberg & Buchanan 1997), society must demand a more informed debate about the medical and psychological realities of serious illness before accepting the legislation of euthanasia as a variable option, for it ultimately represents an inadequate solution to a complex set of issues, putting at risk the frail and most vulnerable in our society. ✣

Professor John Zalcberg, Director, Haematology and Medical Oncology, Peter MacCullum Cancer Institute.

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* The Bill has since been passed by the Senate. This article was originally published in Australian Journal on Ageing, Vol. 16, No.1 February 1997. It is reprinted with the permission of the author and publisher.

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Who Cares and Who is Responsible for Immunising Our Children?

In the previous bulletin the current immunisation schedule, the rates of vaccination and the consequences were discussed. This article will examine who should have the responsibility for immunisation, the possibility of compulsory vaccination and new strategies for boosting Australia's vaccination rate.

Who does the Vaccinating?

Currently in Victoria, vaccinations are usually performed by medical officers and nurses from local municipal councils and by general practitioners. The services that different councils offer in regard to vaccination programs vary. There appears to be no consistency across councils in regard to the amount of funds allocated to an individual immunisation program, or in the number and times of vaccination sessions. Many councils provide comprehensive services with great flexibility to meet the needs of their rate payers but with the introduction of compulsive competitive tendering (CCT) one wonders who will be responsible for quality assurance and the maintenance of these services.

Baby health centres have always been a helpful and informative place for the mothers of young children and babies. In the past the maternal and child health nurse was often the first person to broach the subject of vaccination with a new mother. Informing new parents about vaccination was just part of their overall care for the health and well-being of the baby or child, and by association the whole family. Not only did these nurses provide comprehensive information but they acted as reminders for when vaccinations were due. Our current preoccupation with 'economic rationalism' (counting everything and measuring output) has meant that the baby health centre services offered by some councils have been severely reduced leaving many new mothers with only limited contact. The sort of services provided by baby health services are hard to measure quantitatively. This may have led to an undervaluing of their importance and a corresponding reduction of services in some areas. Ironically, the Australian Bureau of Statistics survey of 1995 found that there was a greater full immunisation rate in children who had been regularly checked at baby health services than those who had not, thereby supporting the role of maternal and child nurses.

The State and Commonwealth responsibilities for providing routine vaccination seem to shift. These governments supply the actual vaccine. In the case of general practitioners in their own practices the Commonwealth Government finances providers through Medicare by funding the consultation during which the vaccination is given. They also provide some of the funding for immunisation programs as well as many comprehensive information pamphlets for parents and guardians, vaccination providers and health care professionals. These in-

formation pamphlets vary in detail according to the targeted reading audience. Not all are freely available in all relevant languages and in such a multilingual society this would seem to be inadequate.

The School Entry Immunisation Certificate

Since 1991 in Victoria to enrol a child in school an immunisation certificate has to be presented. This is a requirement under the Health Act. This certificate gives the following information — it confirms that the child has been immunised against measles, mumps, diphtheria, tetanus, polio, ***or*** that there is a good reason why the child has not been immunised ***or*** that the parent or guardian has undertaken to have the child immunised within the next six months. Providing the school with the immunisation status of the child means that if there is a case of measles or diphtheria at the school the unimmunised children will be excluded for their own protection. While it could be argued that this certificate does not actually increase the numbers of children who are immunised it does make the parents or guardians think about it, and if they have opposition to immunisation this can be documented. It also acts as a reminder to those people who may have started their child's immunisation program but may not be totally up to date with it.

Should Vaccination be Compulsory?

There has been much discussion in the media in recent months about making the vaccination of children compulsory. It has been suggested that unimmunised children should be refused entry into schools, kindergartens and child care centres. Eradication, or at the very least, minimisation of these potentially life threatening diseases is reliant on herd immunity. Herd immunity may be described as the level of immunity in a population when it exceeds a certain threshold so that a bacteria or virus cannot persist or acquire the strength to cause a mass epidemic. Therefore, to achieve herd immunity we rely on each other to be immunised. In fact we have a duty of care to the common good to do so. While we may have the right to decide to forego treatment or actions for ourselves, it is a different thing to do so for others — in this case our children. We also have a duty not to infect others especially those who may be too young to have been immunised, and who therefore, have no resistance to such killer diseases as whooping cough. We live in a community which is dependent on the good will of others. The parental decision to reject immunisation for their own children affects other children at risk — especially those too young to be immunised. This decision also impacts on the community and the health care system which would have to bear the costs of unnecessary disease outbreaks.

"why is the immunisation rate so low?"

The majority of the population actually supports full immunisation. A 1995 Morgan poll found that 74% of Australians felt that children should be fully immunised before starting school with another 21% supporting immunisation for their own children but not wanting to suggest what other people should choose for their children. Therefore, if support for mass immunisation is high why is the immunisation rate so low? The current immunisation rates have not yet been been publicly released despite the existence of the ACIR (Australian Childhood Immunisation Register) since January 1996, so the ABS survey from 1995 is still used to highlight the low rates at 53%. There are many theories which may help to explain this low rate.

Complacency has been one reason offered. Perhaps it is the fact that today's generation of parents have not seen children dying or suffering the sometimes lasting effects of infectious diseases and therefore do not realise what immunisation prevents. Many young doctors have not had the experience of caring for children with these life threatening, but preventable, diseases and therefore may not be as forceful as they should in advising and informing people about immunisation. Perhaps it is the actual immunisation schedule itself which is not user friendly. To be fully immunised according to the schedule can involve the administration of 17 vaccines — a huge memory task and exercise of rigour. Currently there are limited trials taking place using a 5 in 1 vaccine. This vaccine, if proven efficient in achieving immunisation with minimal, or at the least no more side effects than currently used vaccines, may decrease the number of vaccinations any one child may need.
There is however a small percentage

"the autonomous right to choose"

of people (some put this figure at less than 2%) who are firmly opposed to childhood immunisation for conscientious or religious reasons. These people are *informed* in their opposition. They feel that as parents and guardians they have the ultimate responsibility for protecting the rights and well-being of their children as they perceive them. They also feel that they should have the autonomous right to choose what they consider in the best interests of their children. These people are usually unconvinced by scientific data and put forward anecdotal cases to support their anti-immunisation stand and their belief that vaccination can cause adverse effects. Perhaps a no-fault compensation scheme for adverse events following vaccination could be established which would placate these immunisation opponents. While one may not agree with this small percentage of people at least their decision not to vaccinate is informed (however unscientifically based).

It is the parents and guardians who ***have not made an active decision not to vaccinate*** but whose children are not fully immunised according to the schedule who must be given ac-

curate, consistent, ongoing information so that they can make a decision. If that decision is to vaccinate the child then, even with the most vigilant register and reminder service from the local council or the government, it is the parents who have to make a commitment to follow the schedule through.

Financial incentives in the form of cash payouts for vaccinating or withdrawal of welfare benefits for not vaccinating are not the way to boost the immunisation rate. There should be a centrally coordinated body which is responsible for all aspects of the country's immunisation program — not just the statistics on immunisation rates. If this was the case there would hopefully be consistency of information, regular updating, vigilant reminders, equity of fund allocation, and geographical uniformity of program services across the country.

In the beginning of March the Federal Government announced new financial incentives which they hope will boost immunisation rates. This

"they hope financial incentives will boost immunisation rates"

new scheme which will be introduced from 1 January 1998 will penalise those parents who qualify for maternity allowance, child care assistance and child care rebate if they do not immunise their children in accordance with the current schedule. This penalty will be enforced by either limiting the payments given or, in the case of the maternity allowance, only completing the payment when it has been verified that the child has been totally vaccinated according to the schedule appropriate for their age. This scheme does not give those parents who do not qualify for these benefits (because the benefits are means tested) any incentive to immunise. It also seems to imply that people will only do what is considered the 'right' thing if they will be financially rewarded for doing so. Another objection to this scheme is that it does not target those disadvantaged families who do not avail themselves of the child care rebate because of ignorance. Apparently the take up rate of this rebate is low relative to the number of families who use child care and therefore actually qualify for it. These people will hardly be pushed into action and immunise their children because of the threat of losing a benefit which they do not receive anyway. The scheme does however allow for those 'conscientious objectors' of immunisation to still qualify for welfare payments as long as they have a doctor's letter affirming that they have been fully informed of the risks of their decision.

These new government objectives will also offer financial incentives to medical practitioners in private practice through the Better Practice Payment Program in an effort to boost the immunisation rate. This would seem highly problematic as it does not encourage the coordination of a truly national immunisation program if it is left in the hands of private practitioners working in isolation.

Conclusion

The primary purpose of immunisation as a health care intervention is to protect the specific child from infectious diseases but it also has a public health purpose. Obviously the agenda for the government is to increase vaccination rates so that there is only a minimal number, if any, of outbreaks of these preventable, infectious diseases. As the community is a diverse group of people there must be a variety of strategies used to try and achieve this goal. The most important strategy must be education as it is only when you are fully informed that you can make voluntary decisions that are free from coercion and threat of financial punishment. A voluntary informed decision to immunise your child is more likely to be a commitment to see the whole vaccination schedule through than a system of rewards at certain stages of the program. According to Broadfoot "freedom and democracy are highly valued, and people prefer to be asked, rather than forced to do things, even when these are known to be in their best interests. ... most consumers would rather prefer an approach that aims to promote lasting agreement and continuing freedom." The information used to inform the community must be accurate, up to date, reader friendly and not too emotionally charged. ✣

Deirdre Fetherstonhaugh

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Disclosure and Informed Consent

This article discusses informed consent and focuses on what information health professionals should disclose to patients and how important it is that the patient understands the information provided.

The Background of Informed Consent

Considering the long history of medicine, health care and their associated traditions the concept of informed consent appears a relatively new one. The doctor-patient relationship has changed dramatically in the last 100 years. In the past health care professionals, doctors in particular, have acted out of a position of power and authority making decisions on behalf of their patients. Health professionals occupied such a position of trust that their judgement was frequently accepted without question as the best course of action to take. The risks associated with treatments or procedures were not disclosed to, or discussed with, patients until late in the nineteenth century. There are several important aspects to informed consent including: what information the patient needs to make their decision, whether or not patients can make 'informed' decisions while experiencing pain and fear and, how should consent be obtained and by whom. Informed consent involves a patient's informed decision regarding treatment options and is not necessarily satisfied by obtaining a signed written consent.

The standard of information disclosure informed consent requires of health professionals is necessarily related to the standard of information a patient needs in order to give or refrain from giving their 'informed' consent. Also important in gaining informed consent is the need to ensure that patients understand the information provided. Before considering both the standard of information disclosure and the importance of understanding what has been disclosed, it might first be helpful to focus on what generated the desire for gaining patients' informed consent.

Why Gain a Patient's Consent?

Justification for disclosure and seeking patients' consent in the past was governed by the principle of beneficence. The principle of beneficence involves providing benefit and balancing benefits against risks and costs. In the past it was the overriding principle in health care. The primary role of health care professionals was to provide benefits to the patient and this involved assessing the risks and benefits of medical procedures. If harm could be caused as a result of non-disclosure of information then information should be disclosed. For example, if a patient consented to a procedure that resulted in harm, which the patient would not have consented to had they been in possession of all the information, then the principle of beneficence demands that the patient should be informed.

Informed consent in more recent literature appears to be supported by the principle of autonomy. Autonomy in this sense concerns an individual's freedom of choice, their acceptance of personal responsibility and their right to privacy. Informed consent that achieves respect for the patient's autonomy involves: the patient receiving the relevant information on the risks and benefits of possible treatments, as well as their respective probabilities, and respecting whatever choice, consent or rejection, the patient makes regarding treatment. If the relevant information has been disclosed to the patient, and just as importantly, has been understood by the patient, then a patient using their own beliefs and values can make an informed decision regarding their own medical treatment which will ensure that their autonomy is respected.

"autonomy concerns an individual's freedom of choice"

Professional Practice Standard of Disclosure

For informed consent to work effectively in respecting autonomy the patient must be in possession of all the 'relevant information' which the health care professional should disclose. Several standards of disclosure have been suggested, which all generate different sets of 'relevant information' including; the 'professional practice' standard and the 'reasonable person' standard. Before considering an alternative to these standards it will be useful to locate their shortcomings. The professional practice standard states that the extent of disclosure should be determined by the customary practices in a given professional community. That is, a health professional should disclose the same information as a **r**easonable health professional would in the same instance. This standard while accepted in the past as the legal standard, is not ethically sufficient. The professional practice standard, among other things, fails to respect the autonomy of patients. In failing to take into consideration the individual patient the primary goal of informed consent, respect for patient autonomy, cannot be achieved with the patient receiving insufficient or irrelevant information disclosure.

Reasonable Patient Standard of Disclosure

The reasonable patient standard of disclosure also has difficulties. This standard requires a health professional to disclose any information that would be relevant to a reasonable person's decision. This once again fails to consider the patient as an individual. The standard seems unreasonable because it demands that health professionals have a notion of what a reasonable person might consider

relevant and be capable of understanding. Both the professional practice and reasonable person standards fail to satisfactorily capture the level of disclosure which is ethically required of health professionals in gaining informed consent.

Personalised Standard of Disclosure

A more adequate standard of disclosure might be the 'personalised standard' which would include a wider range of information than the previously discussed standards of disclosure. The 'personalised standard' would require discussing with the patient an outline of the procedure or treatment under consideration, explaining what is actually going to happen (or possibly happen) in the procedure or what is going to be administered. A description of any adverse side effects and their probabilities should also be disclosed to the patient along with information regarding possible alternatives, their effectiveness, side effects and risks. The health professional should make a genuine offer to answer any questions the patient has at the time or at any later stage and ensure that the patient knows they can grant or withdraw their consent at any time. A decision might not need to be made immediately in some cases, elective surgery for example, so the patient has time to digest the information and know that they can have a change of mind. This standard of disclosure appears to be especially demanding on the health professional but if used properly would ensure success in gaining informed consent and respecting patient autonomy. Unlike the other two standards discussed this standard takes into account **the patient**.

The Importance of Understanding

In order for this personalised standard of disclosure to be as effective as possible several of its components must be emphasised. When explaining the actual treatment different patients will retain or understand different levels of information but, it is important that all patients have at least a basic understanding of exactly what the procedure or treatment they are consenting to involves. It is not enough

"ensure a common understanding"

that they consent to a tonsillectomy without realising that this procedure involves the removal of the tonsils. To establish that a patient has understood the variety of information that has been disclosed to them it would be useful to have them, the patient, explain it in their own words. When detailing the benefits and risks of a procedure or treatment the health professional must ensure a common understanding of the terms that are being used. For example a doctor may inform a patient that a particular adverse effect is unlikely following a certain procedure. The patient may understand this to mean that there is a one in a million chance that they will in fact experience that particular adverse effect, while in actual fact the adverse effect is present in five per cent of cases. Statistics, where available, are more likely to ensure that both the patient and health professional have a common understanding of the situation.

Focus on the Individual Patient

Allowing the patient to ask questions is an effective way of guaranteeing a patient has received information that while particularly relevant to them, might be almost irrelevant to other patients undergoing the same procedure. If a patient has been informed of the procedure sufficiently and understood the information they will be able to formulate pertinent questions that they would otherwise not have thought to ask. Without at least a basic understanding of what is going on a patient would find it extremely difficult to ask the 'right' questions. Health professionals should be able to draw from the patient's questions what is relevant and important to that particular patient.

The 'personalised standard' of disclosure also allows health professionals to take into consideration the patient's age, intelligence, ethnic background and personality in developing ways of communicating the necessary information. Taking into account the patient will allow health professionals to frame the information in a way the patient will be able to best digest it. The personalised standard allows health professionals to discuss with the patient the risks and possible outcomes that are relevant to the patient. Information about the scarring effect of an operation, for example, will have different significance to different patients. A young girl might have serious reservations about a procedure that will leave a visible scar, while an elderly woman would not have the same concerns about the procedure.

Essential Features of any Information Disclosure

Health professionals are ethically required to disclose information in order to gain informed consent from a patient. Irrespective of which standard of disclosure is considered appropriate, it is not sufficient to simply disclose the relevant information. Health professionals need to facilitate and assist their patients through informed deliberation and ensure that the patient's decision is based on substantial understanding. Health professionals should also be comfortable in telling patients that there is a limit to what is known about a treatment. To say "I don't know" is not a sign of weakness but helps to provide the patient with relevant and accurate information on which they can make their own autonomous decision. Sometimes it might be just as important to know what is uncertain about a treatment as what is known about it.

Health professionals are experts in their particular fields but this does not mean that they are in the best position to make treatment decisions for a particular patient. Health professionals need to be aware that the information they provide patients should be accurate and wherever possible involve

experiences wider and more numerous than their own. For example if a given surgeon has never lost a patient they are not entitled to diminish the risks involved in the procedure because they have never experienced someone dying as a result of that procedure. It is also important to place well publicised side effects of procedures in perspective. If one or two cases of adverse reactions to a certain treatment come to the attention of the media, the weight those risks carry in the deliberation process is likely to be grossly over estimated in the patient's mind. Health professionals should also attempt to ensure that the patient has absorbed more than just the first issue discussed. An ideal way of avoiding such a problem would be to have several discussions with the patient. This would allow them time to assimilate the information and formulate appropriate and relevant questions.

Effective Communication with Patients

A precise standard of disclosure for health professionals to gain informed consent should be developed, but almost just as important for them is to develop communication skills. Experts often have an amazing understanding of the most complex processes but they are unable to explain them to others. When dealing with patients it is essential that experts can communicate their knowledge. In the event that the professional who is to perform the procedure or administer the treatment remains lacking in their ability to communicate to a patient effectively then an adequate disclosure standard should demand that a third party facilitate the required understanding so that informed consent can be gained. 'Telling' patients information is not what is ethically required by any standard of disclosure. What is required is that health professionals help patients **understand** information that will enable them to make an informed decision regarding their medical treatment. ✣

"it is essential that experts can communicate their knowledge"

Tracey Phelan

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Victoria's Infertility Treatment Act

This article gives an outline of Victoria's new Infertility Treatment Act and discusses the laws that regulate the infertility industry in Victoria. It concludes with a discussion about the recent amendments to the Act that abolish the Standing Review and Advisory Committee on Infertility and allow access to infertility procedures to be extended to de facto couples.

Introduction

In 1984 Victoria became the first state in Australia, and indeed one of the first places in the world, to introduce comprehensive laws on in vitro fertilisation. The *Infertility (Medical Procedures) Act 1984* was an attempt to extensively regulate the conduct in Victoria of AI (Artificial Insemination), IVF, Surrogate motherhood and GIFT (Gamete Intra Fallopian Transfer, a procedure whereby sperm and an unfertilised ovum are implanted into a woman's fallopian tubes). Victoria's *Infertility Treatment Act* ("the 1995 Act"), designed to replace the old *Infertility (Medical Procedures) Act* ("the 1984 Act"), was passed during the autumn session of Parliament in 1995 and received Royal Assent on 27 June 1995. In spite of this, most of the Act is not yet in force, and will not come into operation until 1 January 1998. Until that date the 1984 Act will remain in full operation.

According to Clause 1 of the 1995 Act, its purposes are to:

- regulate the use of IVF and other fertilisation procedures such as donor insemination;
- regulate access to information about such procedures;
- regulate research using human gametes, zygotes and embryos;
- promote research into the incidence and causes of infertility;
- make laws regarding surrogacy;
- establish the Infertility Treatment Authority and the Standing Review and Advisory Committee on Infertility and IVF; and
- repeal the 1984 Act

Main Features of the Infertility Treatment Act

Unlike the original 1984 Act, the 1995 Act's definition section is far more extensive, leaving room for fewer ambiguities. According to the 1995 Act, fertilisation procedures or donor insemination may only be carried out by an approved person, or at a licensed place (s.6 and s.7): Approval and licences are given by the Infertility Treatment Authority (see the discussion below).

There are a number of requirements for a couple wishing to have access to reproductive technology. The couple must be infertile, or at risk of passing on a genetic abnormality, they must be given enough information in order to be able to make an informed decision about the treatment, and they must have validly consented to the treatment. The couple must also receive counselling about the treatment procedure they are undergoing. In addition, they must give information to the Central

Register regarding the treatment procedures that were undergone and the outcome of the procedures. However, no *identifying* information about the couple need be given.

"while gamete donation is confidential biological children will be allowed to have access to information about them upon reaching the age of 18"

There are strict regulations regarding consent for the donation of gametes and the use of those gametes. A particular problem noted from the 1984 Act has been rectified: children born from donor gametes are reaching an age where they wish to have some information about their biological parents, are finding that all donors were assured of anonymity at the time and that therefore they are unable to trace them. The 1995 Act ensures that, while gamete donation is confidential, the donors are told that their biological children will be allowed to have access to information about them upon reaching the age of 18. This means that in the future, any child born of donor gametes will be able to trace their biological parents. The legislation is not retrospective however, in order to protect the identity of those donors who were assured at the time of their donation that they would remain completely anonymous.

There is also strict regulation of research into the area of reproductive technology. There is an outright ban on all destructive research on embryos, and any other research must have prior approval from the Infertility Treatment Authority. In addition, research cannot be carried out unless the donors approve. There are a large number of prohibited procedures, including alteration of embryos, obtaining gametes from foetuses or dead people, mixing human gametes or genes with animal ones, cloning, sex selection except in the case of a known genetic abnormality, and producing embryos for the express purpose of experimentation.

There are exhaustive regulations regarding record keeping, the storage of embryos and the giving of approvals and licences to carry out treatment procedures and research. These have been altered slightly in the last few months with the change in the Standing Review and Advisory Committee on Infertility and the Infertility Treatment Act.

Infertility Treatment Authority and Standing Review and Advisory Committee on Infertility

The 1984 Act made provision for a Standing Review and Advisory Committee on Infertility ("SRACI"), the function of which was to approve or reject infertility procedures and experimentation, and also to advise the Health Minister on matters relating to infertility. SRACI answered a need in the community to provide some sort of watchdog which would oversee the infertility industry, ensuring that, as Committee chairperson Justice Ken Marks QC says, "community concerns about what takes place in an industry which intermeddles with human ingredients to create life" are addressed.

'"Community concerns about what takes place in an industry which intermeddles with human ingredients to create life"'

The 1995 Act originally provided for a similar committee: Part 10, Clause 141 stated that SRACI was to advise the Minister on matters related to infertility and also to advise "without delay" of developments in research or treatment for infertility. However, unlike SRACI under the 1984 legislation, the new committee no longer had *sole* responsibility for the approval of applications for research on zygotes or embryos by doctors or scientists. This responsibility was to be shared with a new body, the Infertility Treatment Authority ("ITA"). This new authority comprises six members and its function, which is outlined in clause 122 of the 1995 Act is described by the Health Minister as "a regulatory and monitoring body with the responsibility for granting licences and approvals to hospitals, doctors, scientists, counsellors and research institutions involved in the practice of assisted reproductive technology together with the responsibility for the keeping of a central register of the details of children born of donor procedures and of the donors." Essentially, the role of the ITA mirrored that of the SRACI: any institution wishing to carry out reproductive technology research or treatment needed prior approval from both bodies before licences would be granted and treatment authorised.

In May of this year the Victorian Parliament passed the *Infertility Treatment (Amendment) Act* which abolishes the old SRACI. The reasoning behind this was based on the fact that most of the SRACI functions were being superseded by the ITA. According to the Health Minister both the Chairperson of the ITA, Professor Louis Waller, and the Chairperson of SRACI, Justice Marks QC, wrote to him independently requesting the repeal of the provisions relating to the SRACI. In Parliament the Health Minister said that some of the fundamental problems cited by both Professor Waller and Mr. Marks included:

- extended delays and difficulties in the administration of research approvals involving two bodies, particularly as the applications will already have been approved by the ethics committees of the relevant hospital or institution.
- duplication of the cost in the establishment, maintenance, research and administrative support of the two bodies; and
- overlap of roles and responsibilities in the areas of advice, public statements and policy directions.

As a result of these submissions, Parliament agreed to repeal the whole of Part 10 of the 1995 Act dealing with the SRACI.

However, while many of the regulatory and approval powers of the SRACI have been passed on to the

ITA, there is now no body to provide independent advice on new techniques and treatments to the Minister. Consequently, in his Second Reading Speech in which he proposed the abolition of the SRACI, the Minister for Health claimed that he would be establishing a broad-based ministerial advisory council on infertility issues: the Council will provide direct advice to the minister on all the policy issues related to reproductive technology, including medical, ethical, scientific and consumer concerns. Accordingly, the ITA will then be able to concentrate on its primary role: regulation, administration and monitoring of the industry.

Details of the membership of this new advisory council have been sketchy however. The minister has said only that membership will "embrace the key stakeholders and interest groups in this area." It is to be hoped that membership of the council will accurately reflect, not just the groups with a particular interest in reproductive technology, but also the general community, and that the council will continue, and the SRACI did, to reflect community interest and concern in this vital and contentious area.

Changes to de facto Status

In addition to repealing the provisions relating to SRACI, the *Infertility Treatment (Amendment) Act* also changes the law relating to *access* to infertility treatment. Under the 1984 Act, and the original wording of the 1995 Act, only married couples had access to such treatment. However, in March 1997 the federal Human Rights Commission ruled that three de facto couples who were refused infertility treatment by the Royal Women's and Freemason's hospitals had been discriminated against. In the light of this ruling, and the fact that the couples involved said that they would be seeking to have Victoria's IVF laws invalidated, Parliament felt that it had no choice but to amend the legislation and broaden access to infertility treatment to include de facto couples.

Under the changed legislation "de facto relationship" is defined in clause 6 as "the relationship of a man and a woman who are living together as husband and wife on a genuine domestic basis, although not married." In addition, the definitions of "husband", "wife" and "spouse" are broadened to include partners in de facto relationships. In line with the Government's stated desire that the welfare of any child born as a result of a treatment procedure is paramount, the Health Minister's assurance in Parliament was that the "amendment does not open access to treatment to single women or to same sex couples." He continued, "the definitions of "de facto relationship", "husband", and "wife" and "spouse" contained in this amendment clearly and unambiguously refer to males and females living together." As a result of these amendments, references throughout the 1995 Act to the terms husband, wife and spouse refer to either a married or a de facto couple.

"If a couple claim to be de facto ... the hospital will ... have to take the couple at their word"

Interestingly, in spite of the minister's words, the definition of "de facto" does *not* necessarily rule out IVF access to either single women or same sex couples. As there is no legislation on who is to determine whether a couple is genuinely de facto, and how that determination is to be made, hospitals will be left in the unenviable position of having to assess couples themselves. If a couple claim to be de facto then the hospital will have to either conduct some kind of investigation to assess whether they are, or will simply have to take the couple at their word. While it is recognised that, due to the Human Rights Commission ruling, the Parliament had little choice but to amend the legislation, it is regrettable that more effort was not made to ensure that the amendments *are* genuinely "clear and unambiguous" and that hospitals are not left with the task of assessing the domestic status of applicants.

Conclusion

One way to assess whether couples *are* genuinely de facto is to require *proof:* joint bank accounts and both their names on household bills like telephone, electricity and gas would seem to be the most obvious. In addition, there should be a requirement that they have been together for some time: perhaps there should be two years worth of bank and household records. This would preclude couples who had only been together a short time from gaining access to the treatment.

In addition, bearing in mind that the Health Minister stated that the well-being of the child is the most important priority, perhaps some amendment to the Commonwealth *Sex Discrimination Act* could be contemplated, in order to preclude single women and same sex couples from going to the Human Rights Commission and claiming discrimination. It is clear that when the *Sex Discrimination Act* was enacted in 1984 it was not envisaged that it would be used in such a way. ✣

Anna Stokes

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Duty of Care for a Fetus with a Lethal Abnormality

Many mothers are very distressed once they learn they are carrying a fetus with a lethal abnormality. This article discusses whether it is morally permissible to induce labour in these cases before term, and if so, how early.

From 12 to 16 weeks in gestation antenatal diagnostic tests are now able to detect some lethal congenital defects which cause infants to die soon after birth. Examples of untreatable lethal defects are anencephaly where the upper brain and cranial vault fail to form, various malformations and some chromosomal defects.

The Ethical Problem

"Does the duty of reasonable care owed to fetuses morally permit the induction of labour once a lethal diagnosis is made with certitude?"

While many mothers are willing to allow these pregnancies to go to term others find it too distressing, knowing that their babies will inevitably die of their lethal abnormality soon after birth. Does the duty of reasonable care owed to fetuses morally permit the induction of labour once a lethal diagnosis is made with certitude?

Medical Information for Induction of Labour

A healthy fetus cannot live outside the womb before 20 weeks beyond a few minutes. Some lethal defects cause neonatal death sooner than others, e.g. 86% of anencephalic neonatal infants die under 24 hours and just over half of these die within an hour. The cause of death is usually an incapacity to inflate the lungs due to lung immaturity and the absence of hollow airways. Before neonatal intensive care (NICU) was introduced the threshold of previability was 28 weeks.

Case for Induction from 16 Weeks

Since these fetuses will never actualise their potential to exercise rational and personal acts a moral case is made for inducing premature labour once the diagnosis of a lethal abnormality is confirmed with certainty from about 16 weeks. Once it is agreed there is no moral duty to use extraordinary means to sustain life, the mother would be justified in withdrawing her disproportionately burdensome life support from her fetus who is doomed to die soon after birth. Admittedly some mothers could do this in good faith. It is held that this would not be a lethal act nor *direct* abortion provided the fetus is not intentionally killed.

Case against Induction from 16 Weeks

There is much appeal in these reasons, yet they are not entirely convincing. Nobody has presented a conclusive philosophical argument to show that even the anencaphelic fetus and infant do not warrant personal status nor the moral respect due to persons. In any case, the benefit of any reasonable doubt should be given to the deformed fetus. It is as immoral to unduly risk the life of a previable lethally deformed fetus, including the anencaphalic fetus, as any other dying human being.

"The induction of a normal fetus from 16-28 weeks' gestation would be like drowning the infant in fresh air due to lung immaturity"

Granted we are dealing with fetuses with lethal abnormalities, it would unduly prolong the dying process to employ NICU after early induction. The induction of a normal fetus from 16-28 weeks' gestation would be like drowning the infant in fresh air due to lung immaturity. The demands of justice and of the duty of reasonable care rule out the deliberate termination of pregnancy for a fetus who has no reasonable chance of survival outside the womb.

Case for Induction after Viability

"It seems unreasonable to require a mother to take her pregnancy to term, only to await the imminent death of her child"

There is no moral necessity for pregnancy to go to term, regardless of the circumstances, as though the pregnant woman were an incubator. It seems unreasonable to require a mother to take her pregnancy to term, only to await the imminent death of her child. Births of normal infants are routinely induced by up to two weeks for the medical health of the mother or even for reasons of personal or social convenience without any detriment to the health of the baby. Granted the use of NICU would not be appropriate for a dying infant, it seems the moral respect due to such a fetus could be reconciled with a compassionate desire to alleviate the anxiety of the mother. This could be done by inducing labour at a stage when a healthy fetus would have a reasonable chance of survival without NICU. Henry Davis summed up the consensus of moral theologians prior to the availability of NICU when he wrote "Expulsion of the fetus between the seventh and ninth month is premature birth or acceleration of birth, not abortion."

Knowing that clinicians vary in their assessments, induction of these fetuses from, say, about 33 weeks seems reasonable since healthy infants have a two out of three chance of survival seven weeks before term. In effect, the early induction of labour from 33 weeks would not expose infants with a lethal abnormality to any new risk of death beyond that of their own inherent lethal abnormality. Hence early induction would not be the cause of their death.

Conclusion

It seems, then, the early induction of labour of fetuses with lethal abnormalities would be morally permissible under the following conditions:

1. Pregnancy should always be allowed to continue until the stage when a normal fetus would be viable, i.e. mature enough to have reasonable prospects of surviving, without recourse to extraordinary means of treatment.

2. Taking into account the mortality risks of the lethal abnormality of the individual fetus during pregnancy, normal labour and after birth, induction should not be commenced so early as to cause, or unduly hasten, the death of the fetus due to immaturity as distinct from the lethal abnormality.

3. Early induction should not be initiated unless the diagnosis of the fetus' lethal abnormality is certain, and the mother, fully informed of the procedure, asks for it to alleviate her distress and there are no additional risks foreseen for her life or health.

4. Without prejudice to the first condition, the method and timing of induction itself should be reasonably designed to achieve a live birth with the least possible pain and distress for the unborn child.

5. Comfort and nursing care, including nutrition according to need and appropriate to the condition of the infant, should always be provided.

The US Committee on Doctrine of the National Conference of Catholic Bishops made a statement that is in substantial agreement with my conclusions: *"It is clear, that before 'viability' it is never permitted to terminate the gestation of an anencephalic child as the means of avoiding psychological or physical risks to the mother. Nor is such termination permitted after 'viability' if early delivery endangers the child's life due to complications of prematurity."* ✣

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