



# OTAGO BIOETHICS REPORT

Incorporating Bioethics Research Centre Newsletter

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## Editorial



International participants at the Bioethics Seminar in Dunedin in November included Board Members of the International Association of Bioethics, photographed at the Seminar venue, Knox College. More news about the seminar can be found on page 13

A few years ago when a number of us were involved in establishing the Bioethics Research Centre, we felt we were treading new ground, although we were far from the first in setting up such a Centre. Nevertheless, it was a first for New Zealand. Since that time, bioethics has become established within New Zealand as an essential ingredient of serious public dialogue, it has a part to play in an increasing number of undergraduate courses across a range of disciplines, and it has become established as a legitimate scholarly endeavour within tertiary institutions.

Features such as these are borne out by a number of the articles in the present issue of the *Otago Bioethics Report*, although the two book reviews make it equally clear that there is still a great deal of work to be done in many quarters. Other articles emphasize the ongoing nature of bioethical debate, whether one is dealing with issues in hospice care, legal issues such as the distinction between medical manslaughter and medical neglect, or the means society uses to deal with genetically modified organisms. We are also reminded in this issue that ethical reflection has to take account of cultural perspectives,

so that some elements of bioethical debate within New Zealand should reflect a specifically New Zealand context.

It should come as no surprise to us, therefore, that bioethical debate is far more extensive than many may have assumed. This has become evident to me as an anatomist, as I have become aware of the multi-faceted relevance of ethical discussion within my own speciality, not noted traditionally for its interest in such matters. For instance, we can no longer ignore the means used to obtain cadavers for teaching purposes (that is, whether we use bequeathed or unclaimed bodies). This is not an isolated consideration, since the conclusions we arrive at here have repercussions ethically for the means used to obtain organs for transplantation, and also for the strictures imposed on the use or otherwise of a large range of human tissues and human material. Anatomists have contributions to make to discussions about the nature of fertilization and the status of the human embryo (pivotal considerations these days in so many reproductive debates). Not that many years ago only some of these considerations were regarded as of ethical interest. The others were matters to be dealt with in pragmatic terms, or they were viewed as essentially scientific questions.

However, to state that issues such as these are now of ethical interest does not make them the exclusive preserve of moral philosophers and ethicists. While such as these have a unique contribution to make to the debates, this does not exclude the contribution of anatomists (or any other interested professional group). Bioethics is a multidisciplinary endeavour, necessitating the input of many

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## Case Conference

relevant parties. This is because it is these other parties who are frequently in a position to map out the contours of the debate, and even the tenor of some of the questions to be asked. It is fitting, therefore, that ethics committees comprise those from broad sections of the community, who are able to bring with them a wide variety of expertise and understanding.

Besides these considerations, the Bioethics Research Centre fits within a university community, and so one has to ask whether it also has a contribution to make to university life in general. This may take it beyond the well-delineated confines of biological and biomedical debate, but it is hard to see how it can fail to have an influence on wider debate and wider thought as an offshoot of its primary task within bioethics. Ethical considerations are as relevant across all aspects of university life as they are across all aspects of the biological sciences, clinical medicine, and health care.

This is the realm of 'university ethics', the dimensions of which are indeed extensive, including areas recognised as having an ethical dimension, such as equal opportunity and harassment issues, and scientific fraud and plagiarism. However, ethical analysis and debate also have a seminal contribution to make to issues ranging from academic freedom (and what this means in practice), and accountability at all levels within management and staffing and student interrelationships, to freedom from discrimination, the existence and structure of student fees, and fairness in staffing matters and in many facets of resource distribution.

One can readily argue that there is a close correlation between educational standards and ethical obligations. Any resulting ethical tensions lead to a need to balance the various competing forces at work, and hence to a serious commitment to understand them and hold them in creative tension. This may not lie within the ambit of the Bioethics Research Centre, but my hope is that the existence of the Centre will serve as a stimulus to vigorous debate within this wider sphere.

Gareth Jones  
Acting Director

Jane, age 16, was admitted to her local hospice in the terminal phases of her struggle with cystic fibrosis.

This is a recessively inherited disease of the exocrine glands; those glands which produce sweat, saliva and digestive juices. Thick tacky secretions tend to obstruct the airways leading to repeated severe chest infections with prolonged and severe coughing. There is no cure for this condition.

From her earliest childhood Jane had had frequent admissions to the public hospital for treatment of her chest infections. Antibiotics were no longer effective in treating these.

On admission she was in severe distress with shortness of breath, and cough and chest wall discomfort from the forced respiratory effect and her coughing. She was only able to sit bolt upright and had not been able to lie down during the previous three days because of the additional respiratory effort required. Because of this she had been able to get only minimal sleep and her family had fared little better. Jane and her family were exhausted.

Morphine, which is commonly used in the hospice to relieve shortness of breath, could not be used because it produced a very unpleasant sensation in that she felt she could not cough effectively, something she relied on to enable her to continue breathing. It also caused her to sweat, increasing her discomfort. Her mother was able to provide some relief of her chest wall discomfort by massage. At this stage in Jane's admission the family's role in providing care had been largely passed over to the hospice team and the family had some opportunity to rest physically. However Jane's mother was not able to leave her daughter for more than a few minutes because of her daughter's total physical and emotional dependence.

Whilst in the hospice Jane frequently expressed the wish to die and not have to suffer any more. Both she and her father were Roman Catholic, and after receiving Mass she became a little calmer.

Jane and her family continued to request that 'something' be done. The hospice position of non support of active euthanasia was discussed in some detail with Jane and her family.

The one course of action that was felt to be a possibility by the hospice team was an attempt to induce some sort of light sleep with drugs, although by doing this there was a very high chance that her death would be hastened because of the reduced respiratory drive. If this was offered it was almost certain to be accepted by Jane and her family.

### COMMENTARY 1

Jenny Galbraith  
Hospice Nurse

The Hospice movement claims that all people with a terminal illness have an entitlement to palliative care, and that they have the right to choose the kind of support they prefer, and be involved in decision-making. Palliative care implies that almost all suffering can be alleviated by drugs and other treatments, but Jane's situation illustrates the reality of the limitations we sometimes face with certain symptoms. It takes little empathy to understand how both Jane and the family are feeling, and it appears that they are united in asking that "something" be done.

The care of the dying adolescent is one of the more difficult tasks in medicine, for all professional care givers. Because of their age the switch from curative, or active, to palliative treatment is not a decision that is easily or quickly made.

My comments in this case presentation are not based on experience of nursing dying adolescent patients because so few are admitted to hospice programmes (this in itself raises many questions) but simply on how one approaches this dilemma for any patient.

It is important initially that all the hospice team, as well as Jane and her family, are agreed that this is the terminal phase of her illness. The emphasis on her care medically then is palliative, and the prime objective