

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 effort 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

must surely be her comfort, and a chance to end her days as peacefully as possible. From a nursing perspective we would be seeking to respect Jane's wishes, affirm her individual worth and to support both her and her family in what is an emotive and frightening situation.

Jane will have grown up knowing her life expectancy is short. She would be no stranger to hospitals, infections and interventions. I expect her to be more aware than anyone else as to how much further suffering she is able to endure, and I would trust that all concerned are listening carefully to her. I can think of no more distressing situation to be in, than to struggle to breathe, to be unable to relax as each breath becomes a herculean effort. If sedation is offered the motivation is surely compassion, and the intention is to relieve suffering.

I will look briefly at the principle of beneficence, what constitutes beneficence, and how it relates to other ethical principles. One thinks of words such as mercy, kindness, caring, obligation to assist, and at a deeper level, our relatedness to each other, and our capacity to feel the needs of others. If drug induced sleep were to be offered I would see this as a beneficent action, which at the same time respects Jane's autonomy. She appears to be acting rationally and to understand both the benefits and the risks involved.

Non maleficence or, "above all do no harm" is understood only in the context of how one defines harm. Those who see the possible hastening of death as harm, would not see the above as beneficent. If however, we accept death as a meaningful part of life, offering relief from suffering for Jane, and a death her family can remember as peaceful, then I cannot accept this as harm.

I seek links here between non maleficence and justice. The ultimate foundation of the principle that prevents us from harming others, is surely justice. We must treat every person with equal consideration and respect - we must offer Jane the same relief when dying, as we would were she forty-six or eight-six.

In conclusion then, I accept that death and dying present some unique problems in this age group, such as loss of control (when all one's natural instincts are for control and mastery) and the role of parents, siblings and

peers. Ultimately I do not see Jane's age as the central issue, but rather what hospice care represents. Freed from the focus of curing, it is a philosophy that encompasses spiritual, emotional, physical and family care, and at its very centre, is the belief of a good death, and relief of suffering.

COMMENTARY 2

Tom O'Donnell, MD

Wellington School of Medicine

The sad clinical case information outlined here is not what we aim for now for those with cystic fibrosis. Thanks to a much greater understanding of the disease, current treatment in infancy and childhood is more effective in maintaining reasonable pulmonary health. The modern approach is based on close attention being given to high calorie nutrition taken with much improved and better tolerated digestive enzyme preparations, physiotherapy, the aggressive treatment of respiratory infection with newer, more effective antibiotics aimed particularly at *Pseudomonas* bacteria, and even lung transplantation. Under current evaluation is the use of the enzyme DNase inhalations to facilitate sputum clearing. Also, current research based on the discovery of the specific gene abnormality, in those with cystic fibrosis, has led to the studies involving techniques of possible gene replacement within disordered cells using carrying vectors such as the adenovirus of common respiratory infection. Relevant to many ethical matters associated with this disorder, such progress in our understanding brings much hope for the future for those with cystic fibrosis.

After her frequent previous admissions to hospital, Jane is now presented to us after admission to a hospice and surrounded by a loving and caring mother and family who, like Jane, are now physically exhausted. Jane is in severe distress with her difficulty in breathing. There is a claim that morphine cannot be used for relief because of adverse effects which increase her distress. She is unable to clear the secretions in her breathing passages and it is to be presumed that she has received, without benefit, available antibiotics. The objectives of treatment are to relieve distress and to treat underlying disease processes leading to that

distress. Both of these are proving particularly difficult with Jane. The administration of oxygen to reduce the demands on breathing is not described but is to be presumed. For the relief of Jane's distress by medication, morphine has the best chance of success in spite of its respiratory and cough depressive potential. The possible use of sedative drugs is raised. The hope of inducing some comfort through "some sort of light sleep" is a forlorn one. The persistence of severe breathing distress in an induced confused somnolent state, is likely to be a state worse than without such sedative medication. The regimen of medication which I would recommend in such circumstances, would be to undertake afresh a trial of morphine doses aimed at achieving at least some relief of overall distress. Hospice staff are experienced with such an approach. With their professional expertise, exercised with concern and compassion, they will provide a depth and breadth of emotional, as well as physical, support of both Jane and her family.

Jane has expressed her very understandable wish to die. It is unlikely that she is asking to be killed. The right to die is not to be confused with a claim of a right to be killed on request. It is wrong to expect a doctor to act with intention to kill. The doctor has the right of personal autonomy. It is relief of distress which Jane and her family are seeking. The objective of relieving the distress even if it requires the administration of medication which may lead to lethal complications is to be differentiated from administering medication aimed specifically at terminating life. The grieving of the family should Jane die may be complicated by a sense of guilt if they have been party to a decision to "kill" regardless of the wording with which such an action may be expressed.

The major purpose of a hospice is a positive one; to provide an environment aimed at minimising distress, not just by medication but through personal warmth of caring love, listening and consistent overt support. Palliative care administered by specialist staff within a hospice involves an approach tailored to the individual patient's needs in overall care and including attention to a requirement for a particular regimen of medication. The result is usually an atmosphere which would satisfy the request of Jane and her family for "something to be done".