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# BIOETHICS OUTLOOK

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## In this issue

◆ This last issue of *Bioethics Outlook* for 1998 is devoted to the presentation and discussion of a protocol entitled *Ethical Guidelines on withdrawing or withholding of life-sustaining treatment*. These guidelines were recently adopted by St Vincent's Hospital in Sydney.

◆ In an introduction to the guidelines, Bernadette Tobin describes both their origins and the procedures involved in their preparation.

◆ The guidelines themselves are then set out in full. We hope that they will be of interest and use to others who are thinking of preparing their own protocols or guidelines. We ask that the source of these guidelines be acknowledged in any published use which is made of them.

◆ In a commentary on these guidelines which follows, Gerald Gleeson discusses their value and indicates how they might be used to resolve some 'hard cases'.

◆ Finally, it is high time we officially welcomed Linda Purves to the Centre. Linda has taken over the role of Administrative Officer. We hope that she will enjoy a long and happy association with us.

## Preparing a clinical ethics protocol: the process

Bernadette Tobin

The *Ethical Guidelines* published in this edition of *Bioethics Outlook* have had a long gestation period in the work of the Bioethics Consultative Committee at St Vincent's Hospital in Sydney. Because they are a good example of the work this Committee does, they provide the occasion to reflect on the process and procedures used by the Committee, and on the way such committees contribute to the mission of Catholic health care.

The Bioethics Consultative Committee at St Vincent's Hospital is charged with the task of identifying critical issues in the provision of health care and medical research, considering their ethical, theological and legal aspects and, where appropriate, formulating policies and protocols consistent with the Code of Ethics of the Sisters of Charity Health Service.<sup>1</sup>

One such issue - or cluster of issues - is associated with the forgoing of life-sustaining treatment by patients who are either extremely ill or nearing the end of their lives (or both). Decisions about whether certain interventions should even be offered to patients, and about whether (if offered) these interventions are better accepted or forgone, are often difficult ones, both clinically and ethically. Hence the Committee's recently promulgated *Ethical Guidelines for withholding or withdrawing life-sustaining treatment*.<sup>2</sup> They are set out on pages 3,4,5 and 6.

The protocol has four sections. In the first section, general principles which form the ethical and clinical background to particular decisions about withdrawing or withholding medical treatments are set out. In the second section, these principles are used to ground specific advice about five forms of treatment often relevant to gravely ill patients: the use of (1) antibiotics, (2) cardiopulmonary resuscitation, (3) ventilation, (4) dialysis and (5) nutrition and hydration. In the third section, the steps in the decision-making process are elaborated. In the final section, a short sketch is provided of two background ethical issues: the distinction between judgments of 'sanctity of life' and 'quality of life', and the debate over the provision of nutrition and hydration.

These are not the first guidelines on this subject formulated by the Committee. Since its inception in 1983, ethical issues associated with appropriate withdrawing or withholding of medical treatment in a public, tertiary care hospital have formed a continuing focus of the Committee's deliberations. Over the years the Committee has made several published contributions to good clinical conduct and wise decision-making on this subject. For instance, in 1990 it published a paper entitled '*Cardiopulmonary Resuscitation and Life Support*' in its own occasional series entitled *Reflections* and, in 1994, a revised version of that document was promulgated by the hospital as an Executive Bulletin under the heading *Cardiopulmonary Resuscitation*.

Though the Committee recognized the desirability of some form of active, educational follow-up of its guidelines on the use of cardiopulmonary resuscitation, it was not until 1997 that a series of sixteen clinical ethics sessions, based on these guidelines, was held throughout the hospital and the other institutions on the Darlinghurst Campus.

The Committee had recognized however that, in preparing guidelines on the use of cardiopulmonary resuscitation, it had addressed only one kind of scenario within a range of scenarios which raise questions about the proper withdrawal or withholding of life-sustaining treatment. For instance, it had not addressed the troubling question of whether

it might ever be legitimate to withdraw nutrition and hydration from a patient who had become persistently comatose. Several doctors and nurses urged the Committee to address the wider issues in a more general protocol on that subject. It was thus that, in 1995, the Committee held its preliminary discussion of the current protocol.

The actual process of formulating such guidelines is an interesting and a challenging one. A drafting group of two or three people who are all members of the Committee does most of the work. This group gathers protocols and other documents on the subject and prepares a first draft. That draft is then revised by the full Committee, reworded, revised again (and again!), and sent out in draft form to a large group of people: the hospital's administration, nursing administration, the medical board, intensive care, accident and emergency, experienced philosophers and theologians associated with other institutions, lawyers, etc. The drafting group then revise the document again in the light of the suggestions received during this process. Finally the protocol is sent in the form of a recommendation to the hospital's Executive.

A distinguishing feature of the *modus operandi* of the Bioethics Committee at St Vincent's is found in its connections with the Plunkett Centre. Some of the Centre's staff (trained in philosophical ethics, theology or in a health care discipline) are also members of the Committee. The Centre's library holds copies of relevant protocols and scholarly discussion articles. In addition, the responsibilities associated with administering the activities of the Committee are part of the responsibilities of the Centre's Administrative Officer who acts as the Secretary of the Committee.

One final word. This protocol has been written by the members of a Bioethics Committee which is charged with the task of formulating policies 'consistent with the Code of Ethics of the Sisters of Charity Health Service'. The question thus arises: How far is the protocol based on a distinctively Christian conception of ethics? How far does it express a particularly Christian world view? Put

*(continued on page 11)*

# Ethical Guidelines for Withholding or Withdrawing Life-Sustaining Treatment

## with special reference to the provision of nutrition and hydration

### Introduction and General Principles

With the advances of modern medicine, patients, their families and health care professionals need to know when it would clinically and ethically right to withhold or withdraw a particular life-sustaining treatment and thereby allow a patient to die because of his or her underlying condition.

As Catholic health care facilities, we recognise that human life is a gift from God over which men and women should exercise responsible stewardship. Sound clinical decisions depend on our recognition of:

#### *The dignity of every human being*

◆ even when a person is gravely debilitated by illness or injury, or by mental or physical impairment.

#### *The proper goals of medicine*

◆ to prevent, cure, slow down or arrest the development of an illness; to stabilise a satisfactory condition; or to relieve the distressing symptoms of illness.

Competent patients should be enabled to make free and informed decisions about their treatment options, including refusing treatments which they judge to be overly burdensome (assuming, of course, that the patient is not seriously depressed). When patients are incapable of making their own decisions, the senior doctor has responsibility for making the decision in the patient's medical best interests, bearing in mind what can be known of the patient's wishes about treatment in such circumstances.

#### *The need to assess the benefits and burdens of treatment options*

◆ treatment may be withheld or withdrawn if it is judged to be futile or overly burdensome by comparison with its expected benefits. In some cases the burdens of treatment may include excessive demands on family, carers, or health care resources.

#### *The sanctity of human life*

◆ so that even someone who is no longer able to relate knowingly to others or to pursue the ordinary activities of human life is to be provided with all available, appropriate and effective medical treatment.

#### *Respect for patient autonomy*

◆ the patient is the source of the health care professional's right to treat him or her.

# Ethical Guidelines for Withholding or Withdrawing Life-Sustaining Treatment: Some Specific Examples

## Antibiotics

Although pneumonia and similar illnesses can readily be treated by antibiotics, situations do arise in which, because of a patient's extreme frailty, multiple illnesses, or severe dementia, any new medical treatments are likely to be futile or overly burdensome. When this is the case, antibiotics and the like need not be given.

## CPR

The term CPR covers a number of treatment options, many of which would impose great burdens on a frail elderly person, or if successful, would only restore the person to life for a relatively short period of time, perhaps in a gravely debilitated condition. The decision not to instigate CPR is justified if it is judged that the benefits of resuscitation would be disproportionate to the burdens it would impose on the patient.

## Ventilation

Many people have come to lead satisfying and indeed fulfilling lives while dependent on mechanical ventilation. Cases do arise, however, in which patients judge that the burdens to themselves, and/or to others, of using a ventilator are very grave. If so, a decision to withdraw ventilator support may be ethically justified.

## Dialysis

Renal dialysis can be expensive and often involves considerable burdens for the patient. Dialysis would normally be inappropriate if it would involve an unreasonable burden to the patient and/or others, and would only maintain the patient in a precarious and distressing terminal condition.

## Nutrition and Hydration

Nutrition and hydration will be medically futile (and therefore not morally obligatory) when such feeding neither brings comfort nor prevents imminent death, and/or when it cannot be assimilated by a person's body.

While legitimate debate continues about what constitutes "futility" and/or "burdensomeness" in the provision of nutrition and hydration, especially in the case of patients who are persistently unconscious, the presumption should be that maintaining a patient's life is our most fundamental way of respecting the person whose life it is. It follows that nutrition and hydration should be provided for the persistently unconscious patient, unless and until it is judged clearly to be medically futile or unduly burdensome to the patient or others.

In our society, provision of nutrition or hydration does not normally impose significant demands on carers or health care resources.

Good medicine treats a person, rather than a condition. Respect for the dignity of persons requires that they neither be under-treated nor over-treated, but rather have access to whatever care is appropriate to their condition.

## Ethical Guidelines for Withholding or Withdrawing Life-Sustaining Treatment: the decision-making process of consultation, communication and documentation.

◆ Because of the possibility of serious physical or mental illness (e.g. dementia, retardation, depression or psychosis), it will sometimes be necessary to seek a psychiatrist's assessment of whether a patient is competent to make decisions about life-prolonging treatment.

◆ In the case of a *competent* patient, a decision to withhold or withdraw a treatment should only be issued after the senior doctor has discussed the matter with the patient and established that the patient judges that the benefits of the treatment would be disproportionate to the burdens the patient foresees it would impose (except in the rare case in which the doctor believes that the patient has a serious psychological disorder or is suicidal).

◆ In the case of an *incompetent* patient, a decision to withhold or withdraw a treatment should only be issued after the senior doctor has judged that the treatment would be medically futile or that its benefits would be disproportionate to the burdens it would impose on the patient or on the available health care resources.

◆ In making these treatment decisions, the senior doctor should consult with the family, legal guardian, significant others and those involved in the care of the patient, take their views into consideration in making his or her decision, and explain that decision to them.

◆ The senior nurse has the responsibility to communicate and explain the decision to other nursing and allied staff. Family, significant others and the care team should be given appropriate opportunities for debriefing and pastoral care. Sensitivity towards the religious and cultural background of patients and their families and friends is necessary as some faiths and cultures are more reluctant than others to have certain treatments withheld or withdrawn.

◆ The decision, together with a brief statement of the reasons for it, as well as brief notes on the consultation process, should be documented within the patient record, dated and signed either by the senior doctor or by his or her delegate who records this as the senior doctor's decision.

◆ Treatment decisions to limit, withhold or withdraw treatment should be reviewed and documented regularly (at least once a week), and in response to changes in the patient's condition or on the request of a patient or family.

◆ After a particular treatment has been withheld or withdrawn, the patient must continue to be given all other care and attention appropriate to his or her particular condition and to his or her dignity as a human being.

## Ethical Guidelines for Withholding or Withdrawing Life-Sustaining Treatment: Two Background Issues

### The debate over the provision of nutrition and hydration

In the case of competent patients, the general principle about withdrawal of nutrition and hydration is easy to state in terms of medical futility and benefits and burdens. However, the extension of this principle to the case of persistently unconscious patients is much debated by ethicists and clinicians.

The presumption that nutrition and hydration should be provided to such patients is reinforced by the fact that the diagnosis of persistent, and possibly permanent, unconsciousness is often a difficult one. If the patient's condition is thought to be reversible, there is good reason to endure and persist with methods of nutrition and hydration which may involve some burden to the patient or others. So, before a decision to withdraw nutrition and hydration is reached, the irreversibility of the patient's condition must be diagnosed with practical certainty. This is the responsibility of the patient's medical practitioner. Many clinical indications will be relevant to this judgment, above all knowledge of the cause of the patient's injury.

In the case of non-traumatic injury (e.g. stroke, cerebral haemorrhage), a reliable judgment about irreversibility might be possible after a few days. In the case of traumatic injury, a year or more may be required before the irreversibility of the condition can be determined with practical certainty. It is also important to recognise that there are different degrees of unconsciousness within the broad category of lack of responsiveness and awareness.

Moreover, the continued provision of nutrition and hydration is an important expression of solidarity with the patient. The provision of food and water, even by "artificial" means, demonstrates love, care and support: their withdrawal can have a profound significance for grieving family and friends. At no stage should our treatment of a patient allow others rightly to conclude that the patient is being abandoned to die. Even if a decision is made to withdraw nutrition and hydration, the patient must still be given all the care and attention appropriate to his or her dignity as a human being. (For example, the risk of infection must be minimised, and the patient should be positioned regularly and kept clean and dry, with special attention to oral hygiene.)

### "Sanctity of Life" and "Quality of Life"

The phrase "quality of life" is often used in relation to decisions about life-sustaining treatment. This term refers to a person's *experience* of life, with all its mix of fears and hopes, of pains and pleasures, of frustration and opportunity, and especially of relationship with significant others. For patients with chronic and multiple illnesses, some interventions serve only to prolong their precarious and frail condition, and provide no improvement to their general well-being or life as a whole.

For others, treatment may offer some small hope of remission or improvement but require them to endure significant additional pain, anxiety, grave costs and inconvenience.

Thus some patients will accept chemotherapy while others will rightly refuse it. In making these decisions, patients are not choosing between life and death, but — while recognising the sanctity of life — are judging the kinds of burden they are reasonably able to endure.

The term 'quality of life' should never be used to measure the worth or value of persons as such, as if some people's lives were more valuable than other people's lives. No one should ever declare that another's 'quality of life' is so poor that his or her life is 'not worth living'. Behind this declaration is the idea that the life and dignity of every human being is not valuable in itself but is valuable only as a means to 'the quality' of the person's conscious experience and activity (most commonly, as this is judged by others). Typical of the use of this unacceptable notion of 'quality of life' would be the view that medical treatment of one condition (e.g. a bowel obstruction) should be withheld solely on the ground that a patient's quite unrelated condition (e.g. Down's Syndrome) makes his or her life not worth living. Assumptions about 'quality of life' in this sense should never enter into judgments about withholding or withdrawing treatment.

# How the Guidelines may help resolve some "hard cases"

Gerald Gleeson

In many ways, the principles behind the *Ethical Guidelines for Withholding or Withdrawing Life-Sustaining Treatment* are very simple. There is first of all a background conviction about the human responsibility to take care of one's life and health. This conviction contrasts with the spirit of much of contemporary bioethics, in which personal autonomy with respect to one's perceived "interests" is paramount. On this contemporary view, the rightness of decisions to limit or withdraw treatment depends solely on the patient's autonomous choices; and the purported right to voluntary euthanasia (and "physician assisted suicide") is the logical extension of this claim to unlimited autonomy.

By contrast, the Catholic Christian tradition which underpins these guidelines affirms that human life is a gift received (from God), a gift held in trust, over which we each have a "stewardship" responsibility. Medicine helps us to take appropriate care of our lives, by preventing or curing illness, by stabilising a satisfactory condition, or by relieving distressing symptoms. Once the proper goals of medicine are understood in relation to the responsibility to take care of our health, it becomes clear why euthanasia — i.e. intentionally taking life to relieve suffering — could never be "good medicine", nor a genuine exercise of autonomy.

Yet even on this religious understanding of life as a gift received, there are limits to what we must do to maintain our lives. These limits used to be described in terms of taking "ordinary" and "extraordinary" means. There is no obligation to go to "extraordinary" lengths to keep ourselves or others alive. It was always recognised that whether a means were "ordinary" or "extraordinary" would vary from patient to patient and from situation to situation. But the necessary flexibility of the terms "ordinary" and

"extraordinary" is now undermined by the fact that what were once "extraordinary" medical interventions are commonly routine and "ordinary".

For this reason, it is more helpful to speak of treatments as "proportionate" or "disproportionate" with respect to their benefits and burdens to the patient, and/or to others, including the others whose common good is served by the health care system. For any treatment to be "good medicine", it is necessary that the benefits of the treatment (given the probability of success) not be outweighed by the burdens it would impose (chiefly its side effects). "Good medicine" is thus "proportioned" to the good of the patient, so that the patient is neither under-treated nor over-treated. In addition, treatment that is unlikely to be effective is "futile" and so not proportioned to the good of the patient.

The key principle in relation to decisions to limit or stop treatment is thus that "treatment may be withheld or withdrawn if it is judged to be futile, or overly burdensome by comparison with its expected benefits". The *Guidelines* assume that what is called for in making these decisions is "practical wisdom" or a judgment of what is "reasonable" in the particular circumstances of the case. These *reasonable* judgments about the proportion between benefits and burdens are analogous to the judgments juries are asked to make about whether or not a person took "reasonable" care in the circumstances. The notion of "practical reasonableness" is the key to a virtues approach to ethics.

## A virtue ethics as "action guiding"

Critics of an ethics of "practical wisdom" often complain that this approach does not tell us exactly what to do. The critics want an "action guiding" theory, either *consequentialism*, which requires us to calculate

and weigh the benefits and harms of probable outcomes, or *deontology*, which requires us to apply specified principles, like autonomy and beneficence.

Both consequentialism and deontology appeal to a moral standard *wholly external* to the agent, viz. a mathematically calculated assessment of outcomes or a deduced application of a set of rules. Both approaches imply that *any* rational agent can calculate accurately or apply the agreed rules. By contrast, a virtues approach to ethics holds that one's capacity to make important decisions in life, moral decisions in particular, is very much dependent on the kind of person one is. The virtuous person and the vicious person do not see the world in the same way, they do not judge the same things to be desirable or appropriate in the circumstances, they differ about what counts as good or harm, and about what is reasonable in the circumstances. For example, a moderately courageous person will recognise when a difficult course of action is reasonable and ought to be taken, whereas a cowardly person may not even have seen that anything could be done in the circumstances.

Of course there are some contexts in which equitable judgment can be fairly precise, for example about the distribution of goods. In matters of health care allocation, for instance, all members of a society ought to have equal access to basic resources, and there should be a certain mathematical precision to the allocation formula about how the dollars are spent. But apart from clear cut cases of justice, one's capacity to know what to do in significant situations is shaped by the kind of person one is, that is, by one's moral character. The traditional "cardinal" virtues outline those key aspects of moral character — courage, moderation, justice, and prudence — required for sound decision making. A virtue ethics does not prescribe exactly what one should do in certain circumstances, it does something more important: it tells us what sort of people we should become, if we are to have any hope of knowing what to do when "reasonable judgment" is called for.

The cardinal virtues are of two kinds: *courage* and *moderation* refer to make-up of the agent, they name the stable emotional

dispositions without which my judgments are sure to be flawed (e.g. if I am unwilling to face difficulties or if I am too much swayed by immediate pleasure). *Justice* refers to my relationships with others, my willingness to give others what is due to them. *Prudence* is practical wisdom integrating the claims of the virtues.

In most cases that matter, no external code or principle, no calculation of outcomes, could possibly resolve our moral dilemmas, to tell us, for example, whether the burden a treatment would impose on a patient is justified by the expected benefit. A virtues approach challenges our temptation to look for a definitive moral answer outside of ourselves and our own grasp of the situation. Whether my judgment really is morally wise will depend on the extent to which my "moral instincts" are soundly formed, that is, on the extent to which my feelings and dispositions are rightly ordered in relation to myself and to others.

On this virtues account, the standard of moral "reasonableness" is both "internal" to the moral agent, in that in the end I can only trust my own grasp of what is reasonable in the circumstances, and "external" to the moral agent, in that in making my judgment I aspire to an objective standard of what truly is reasonable, what the virtuous and reasonable person would judge right in the circumstances.

It is important to note that a virtues approach does rule out certain kinds of action, viz. those which directly contradict justice or fidelity (e.g. murder, lying, adultery, etc.). These actions are ruled out, not only because they are contrary to a rule or law, or because they generally have bad consequences, but also because they inevitably corrupt the moral agent; they are the kinds of action I cannot perform without damaging my own moral character and integrity, as well as harming others. This is why, in caring for the seriously ill patient, killing the patient is never permissible. However, as the *Guidelines* make clear, there are times when it would be right to withhold or withdraw life-sustaining treatment, even if the patient's death is thereby hastened, either because the treatment would be futile, or because it would impose on the patient



burdens disproportionate to the expected benefit.

### Bringing more difficult cases into focus

I have identified two ways in which an ethics of practical wisdom assists moral decision making: first, by ruling out certain kinds of actions which are inherently wrong, and secondly, by highlighting the moral attributes one needs if one is to be able to make sound decisions. A practical wisdom ethics guides moral decision-making in a further way, viz. by showing how to determine what is "reasonable" in the circumstances of especially hard cases. Two such "hard cases" in relation to withholding or withdrawing treatment are the following: Case A concerns an elderly and severely demented patient, and Case B concerns a young brain damaged child who is both blind and deaf, and unable to move around. Should either of these patients develop pneumonia, it can easily be treated by antibiotics. However, the question arises in the minds of many as to whether it would not be better to withhold treatment, thereby allowing such patients to die of their pneumonia, rather than, by treating them, to prolong their distressing condition and poor "quality of life". Could such a decision be justified as a "reasonable" judgment about the benefits and burdens of treatment? May we "take advantage" of the chance to withhold treatment in cases like these?

The method I propose for reaching a judgment in these "hard cases" consists in our seeking to bring the case "into focus" by comparing it with similar "paradigm" cases in which we are confident of knowing what to do. A reasonable judgment will always lie between two extremes of unreasonable judgment; by comparing a hard case with analogous cases we gain insight into its true moral resolution by seeing whether it lies closer to a paradigm of reasonable or unreasonable judgment.

As the protocol makes clear, it is crucial to distinguish between judgments about the benefits and burdens of *treatment*, and judgments about the benefits and burdens, or the worth, of the patient's *life* as such. Judgments about whether to withhold or

withdraw treatment should not be judgments about whether or not another person should live; they should only be judgments about whether or not a treatment does the patient any good. Futile and burdensome treatments do the patient no good; they are just bad medicine. A straightforward example is provided by cases involving chemotherapy for advanced cancer. Let us identify, as Case C, a case in which chemotherapy might extend a patient's life by a short time, but would also involve seriously debilitating side-effects. The patient is entitled to judge that the burdens it would impose outweigh the potential benefit. A patient who refused chemotherapy for this reason would not be judging that life was not worth living. The patient would simply be judging that a shorter, more comfortable life was preferable to a longer, more burdensome life.

In this example of Case C, we can clearly distinguish between the benefits and burdens imposed by the treatment and the benefits and burdens associated with the patient's condition without treatment. In Cases A and B above, the distinction between these two kinds of burdens seems less clear cut. Dementia and brain damage can be so severely debilitating that it is questionable whether the cure of pneumonia really is much of a benefit, and whether a "side effect" of the cure is to prolong a distressing and debilitating condition. Treatment might also involve burdens which make the patient's overall condition more distressing (e.g. by requiring periods of time in hospital away from carers, etc.).

To bring difficult cases like A and B into focus, I want to compare them with two similar cases which lie on either side of them. In Case D, a baby seriously affected by Down's Syndrome is suffering from a dangerous heart condition which only surgery would cure. The required surgery on one so young would be physically invasive, risky, traumatic, and have small chances of success. The possible benefit of the surgery would be outweighed by the burdens it would impose on the baby (at least at this early age). Hence surgery is rightly withheld in order to spare the baby an unreasonable burden. In Case E, a Down's Syndrome baby develops an infection that can be easily by antibiotics.

Since the treatment would impose no undue burden on the baby, it ought to be given. There is simply no scope for claiming that treatment would be futile or burdensome. In Case E it is clear that, if one were honest, one would realise that a decision to withhold antibiotics could only be based on the unethical judgment that a child with Down's Syndrome would be better off dead.

The difference between Cases D and E consists in the way the benefits and burdens of the treatment options are related to the patient's overall condition. In Case D, the severity of the child's Down's Syndrome makes surgery more risky and less likely to be successful, and so its potential benefit is not warranted by the burdens it would involve. (Similar surgery might be indicated in the case of a child without Down's Syndrome or with a milder form of Down's Syndrome.) In Case E, by contrast, the fact that the child has Down's Syndrome is incidental to the treatment of his pneumonia. Down's Syndrome is irrelevant to the assessment of the burden of treating pneumonia, which is why antibiotics should be given just as they would be given to any other child.

Cases D and E lie on either side of the two hard cases I raised earlier: that of the elderly demented patient (Case A), and the grossly disabled child (Case B). Of course, both these cases are closer to Case E (the child with pneumonia) than they are to Case D (the child with serious heart condition). Is there anything that would differentiate Cases A and B from Case E, or should the pneumonia be treated in all these cases? The difference, I suggest, lies in the fact that in Cases A and B, the pneumonia occurs in the context of multiple illnesses, overall frailty, and grave debilitation, such that treatment of a single illness like pneumonia is likely to have little or no impact on the patient's overall well-being, and/or is likely to prolong, without alleviating, the patient's extremely distressing condition. It is for this reason that one might judge that in Cases A and B the pneumonia need not be treated, even though in the rather similar Case E the pneumonia should be treated.

The legitimacy of this conclusion may be tested by a comparison with two other cases.

In Case C above, a cancer patient chooses to forgo another round of chemotherapy, on the grounds that it will involve severe side-effects. Here consideration of the patient's experience of life *after treatment* is properly relevant to the assessment of its benefits and burdens. In Case F, a frail, terminally-ill patient in severe pain and distress from which there is little relief, finds that the sheer effort to continue eating and so maintain his life is unduly burdensome to him. By not eating, this patient need not be choosing to end his life; he may simply be choosing to be without the burden that keeping himself alive has come to require, viz. the burden of continuing to eat given his overall frailty and otherwise distressing condition.

As in Cases A and B, so in case F, it is difficult to separate the specific burdens of treatment (or of continuing to eat) from the patient's overall condition of frailty and distress. It is for this reason that assessment of the "burdens" of treatment is more broadly based in relation to the patient's total well-being, rather than narrowed to the precise burden of the treatment itself. Thus, even though one should take reasonable steps to maintain one's life, in situations like those in Cases A, B and F, there is scope for the reasonable, and ethically sound, judgment that treatment may be forgone.

### Patient competence

There is, however, one key difference between Cases C and F, and my "hard" Cases A and B, namely the competence of the patient. In those cases where the patient is competent to assess the benefits and burdens of treatment options for himself or herself it is clearly easier for decisions to withhold or withdraw treatment to be arrived at. The patient alone knows what he or she can reasonably bear, and it is properly the patient's right and responsibility to make the decision when competent to do so. The brain damaged child, and the demented elderly person, by contrast, are unable to judge whether treatment will be sufficiently beneficial for themselves. There are two important points in the *Guidelines* with respect to patient competence. The first is that we need to distinguish between competence in general, and competence to make decisions

about life-prolonging treatment. For example, a terminally ill patient may be quite "competent" in a general sense, and yet be suffering from a clinical depression which affects his or her specific competence to make decisions about life-prolonging treatment. The clinical depression can, and should, be treated, before such important decisions are made or acted upon. Often the judgment of a psychiatrist will be required to assess the extent to which the patient's competence is being limited by depression, retardation or psychosis.

The second point is that when a patient has been judged incompetent with respect to decisions about life-prolonging treatment, the senior doctor must take the decision as to whether the treatment would be futile or unduly burdensome. Knowledge of the patient's wishes, and the advice of family and carers, will often assist that decision. However, the focus of the decision always remains that of the patient's best medical interests, with respect to the effectiveness of treatment and the burdens it would impose. The doctor's decision is not simply one of doing what it is thought the patient would have wanted. In the case of incompetent patients, there is obviously a danger that some people will rashly think that the burdens of existence for another person outweigh any possible benefits of treatment. In general, therefore, we must be careful to ensure that decisions to withhold or withdraw treatment from incompetent patients are soundly based on reasonable judgments about the benefits and burdens of *treatment*, not on judgments about the worth of the patient's *life*.

In short, the two hard Cases A and B that I have considered in this article exemplify the complexity that can arise when assessing the benefits of treatment. At times, it may be reasonable to conclude that even what would be ordinary and non-burdensome treatment in most cases would be futile or burdensome for patients whose overall condition is gravely debilitated by multiple illness and frailty. If in doubt, of course, we should err on the side of maintaining life.

## Preparing a clinical ethics protocol: the process

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another way: Does it express a view of the role of (and limits to) medical interventions in people's lives to which any thoughtful person might subscribe? Or are the concepts employed and the principles enunciated ones which make sense only to people with Christian convictions?

This is a big topic. Suffice it to say here that the precepts of the Catholic tradition of health care ethics (its concepts, principles, virtues, obligations, etc.) are proposed as ones expressive of a genuinely human and humane health care ethics. Of course this claim is the subject of much debate, both within and outside that tradition. Whatever the debate about that claim in other areas of morality, however, the Committee hopes that this protocol gives expression to a view of the significance of human life, of human pain and suffering, of the goal of medical interventions and of a sensitive recognition of the limits of curative treatment and the place of palliative care, which will be both accessible and persuasive to many people of no religious belief as well as to many Christians from other traditions.

### FOOTNOTES

1. The composition of the Committee is as follows: a representative of each of the facilities on the Darlinghurst Campus of the Sisters of Charity Health Services (St Vincent's Public Hospital, St Vincent's Private Hospital, St Vincent's Clinic, the Sacred Heart Hospice, the Garvan Institute, the Victor Chang Institute and the Plunkett Centre for Ethics), four special clinical representatives from (Emergency, Intensive Care, Palliative Care and Mental Health), professional representatives (of Medical Staff, Nursing Staff, Allied Health Professionals, Scientific Staff and Administrative Staff), a Lawyer, a Philosopher and a Theologian. In order to maintain a workably-sized committee, one person may act as the representative of more than one group. The Chairperson is appointed by the Hospital's Regional Mission Committee.

2. The guidelines were promulgated as an Executive Bulletin by the Executive Director of St. Vincent's Public Hospital, Dr. Denise Robinson, on 19th October 1998.

# NOTEBOOK

## Advance Notice Intensive Bioethics Courses in 1999

*"Testing the Boundaries:  
Contemporary Issues in Health Care"*

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