BIOETHICS OUTLOOK

*John Plunkett Centre for Ethics in Health Care*

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# Women and Cancer

*Raimond Gaita*

*Women and Cancer*[1] is a moving book. It is written for the most part by patients suffering from cancer at the Mercy Hospital for Women in Melbourne. Some of the contributors died before the book was launched.

There is fine introduction by Genevieve Green a social worker at the Mercy Hospital who played an important role in encouraging the women to write about their experiences. There is also one by Professor Robert Planner of the Department of Gynaecological Cancer at the Mercy Hospital. Planner's deeply felt, tearful address at the book's launch was one of the most moving I have ever heard and made me understand better how his care for his patients contributed to the quality of what they wrote. All the more reason why I felt intimidated by the task of saying something that would not be banal beside the book's achievement. When we are moved we are called upon to be true to the value of what moves us. Almost inevitably we resort to generalities. Philosophers, especially, cannot resist them. Their mind is cast that way, and I am no exception. I feared that I might appear to treat the suffering of the women who contributed to this book, and that of their families and friends, as an opportunity for philosophising....

**Inside**

To begin with I must speak personally, for I know that my recent circumstances affected my response to the book. In the last year and a half two close friends, my father in law and my father died. Death has been on my mind. As it is on the mind of anyone diagnosed with cancer, even when the prognosis is good – for between the first knowledge that one has the disease and the justified acceptance of a good prognosis, there is the confrontation with mortality. It always leaves its mark. Alia Ali, speaks truthfully when she says: "Everyone who has cancer worries about what will happen tomorrow."

Again and again in this book – as Genevieve Green has noted in her introduction – the authors return to the tension between the sense that they are radically alone in their affliction and the comfort found in sharing their experiences with others, in their case mostly women suffering from similar gynaecological cancers and the effects of their treatment. I call this difference between the perception of radical aloneness and community a tension, but I would not call it a contradiction, because that might suggest that truthfulness required that one of these perceptions should be abandoned. That would be wrong, but understandable, for each perception seems to deny the other. The sense of radical aloneness is not only without comfort, it resists it, inclined to judge it an illusion, and also an evasion because it is sustained by the belief that meaning can be found even in this kind of affliction. But from the perspective of one – almost always another part of oneself or oneself at another time - who has found comfort and meaning, this looks like despair driven by fear.

One of the impressive features of *Women and Cancer* is that all the women who speak of this tension resist the temptation to collapse one part of it for the sake of the other. They are true to both and in this they are faithful to life. The same is true of their responses to other tensions they record. The most poignant is that between the pained knowledge that a woman's life has been cut short in her forties and the affirmation that even so, such a life is complete. Bernadette Law expresses that sense of completeness in her poetic eulogy for Colleen Hornsby: "A woman denied her autumn years/Is no less complete for that." But she does not thereby deny the particular sorrow that gains its character because death came for someone "before their time". Anyone who is tempted to that denial would need to find words to respond to Kathy Kambouropoulos who writes with heart-rending passion of her love for her sister Damanda, a cancer patient since 1983 and now fighting for life at the age of 33. The sense of a life cut short and the sense of a life completed in death and by the manner of one's dying, these stand together, neither claiming dominion over the other.

It is a fact, basic to human life, that we are consoled by knowledge that others suffer as we do and must die as we must. That might seem like consolation achieved for unworthy reasons, but really it does not express an inadequate concern for others. It is an expression of the fact that we are creatures who seek to make sense of our lives. The need to make sense is not driven only by a response to one's own suffering, but also by a more general need to understand what it means to live a human life, and what death shows us about that meaning. Death is so fundamental to our sense of who we are, that only when we come seriously to contemplate it do we gain any real understanding of ourselves. Even if someone thinks seriously about death only when they are dying, they must think of death as something that comes to us all, and not merely as affecting us all, but as defining our condition. The ancient Greeks thought death so important to the definition of humanity that they called human beings "The Mortals".

The testimony of the authors of *Women and Cancer* is that the Greeks were right. They all speak of gaining a perspective on their lives, on what matters and what does not from the perspective of a potentially fatal illness. There is no category more fundamental in our assessment of ourselves and our lives than the distinction between the real and the counterfeit - are we really in love or is it love's counterfeit, infatuation; are we really grieving for this person or are we sentimentally indulging ourselves; do money and status really matter? and so on. The philosopher Plato said that we human beings characteristically mistake the necessary for the good. He meant that we are prone to treat as the source of value the things which have become necessary to us because we think that without them our lives would be meaningless. They are the things to which we give nearly all our energies when death seems distant - money, status, career and so on. Not one of the women flatly denies the importance of such things, but they constantly imply and sometimes they say directly, that we should trust our sense of their value only if we see them in the light of a lucid sense of our mortality. Only then do we deserve to be confident that we have real coinage.

Isak Dinisen said that "all sorrows could be borne if you put them into a story or tell a story about them". The women who contribute to this book testify to what is true in that. But, as I said at the outset, they are also true to something that denies it. For if it is a basic fact of human life that we are consoled by the knowledge that our suffering is shared, it is also a basic fact that we fear death in a way that is primitive and beyond the reach of the consoling power of stories and poetry.

This primitive fear of death is sometimes thought to be the same fear that we see in animals. Aspects of it are like that; to deny it would be to deny our creatureliness. But an irreducible element in it is distinctively human for it is tied to the fact that there is something mysterious about the disappearance of the human personality. No natural story about what happens to the body and no supernatural story about the survival of the soul – however true they may be - can diminish that mystery and the pain that goes with it. One cannot understand who one is, the identity that distinguishes us from others, without a sense of what one has in common with others. But equally, in their application to human beings, the concepts that identify what we have in common require us fully to acknowledge that each of is unique and irreplaceable – unique in a way that nothing else in nature is.

The concept of mortality is pre-eminent amongst those that mark what we have in common. But it is the uniqueness and preciousness of each human being that gives to our dying the significance, the sorrowful resonance, that the Greeks captured when they called human beings "The Mortals". The same accent of sorrow and pity is found in the prayer for the dead in *The Book of Common Prayer:*

> *Man that is born of woman hath but a short time to live and is full of misery. He cometh up and is cut down like a flower. He fleeth as it were a shadow and never continueth in one stay.*

The need both to acknowledge our commonness and also our radical individuality, and the fact that we cannot do one without the other, creates an irresolvable tension that is expressed in this book as being between aloneness and the consolation to be found in community. That tension and the fact that it is irresolvable lies at the heart of our mortal identity. The head alone will never really understand it. Understanding is given only when head and heart are inseparably combined.

It is a form of understanding that has special vulnerabilities. That is why more than one of the contributors speak of being on an "emotional roller-coaster", disoriented by the alternations of hope and despair, comfort and the fear that denies it. Honesty about that – brave and undramatic – marks every contribution to this book that is written by the patients themselves.

The wisdom shown in this book requires emotion, but none of the stories in this book is emotional in the sense that should invite criticism. I do not recall a note of self pity or self dramatisation. The stories are often heartbreaking, but that is partly because of their matter-of-factness. Much of the profundity of this book lies in its matter-of-fact attention to detail. The detail is feminine. It could hardly be otherwise in a book written by women. But the attention to detail, or rather the quality of this attention to detail, is also feminine.

A friend once said to me that he believed that women are finer than men. Instinctively I agreed, but it is not easy to say exactly why. Reading this book, I remembered his words. I believe that men are unlikely to have written a book so impresive, or at any rate, impressive in this way. The women speak out of deep suffering, often with the prospect of death and always with the fear of it. They say that from this perspective they have come to see what is really important in their lives. Yet they often speak of hair loss caused by chemo-therapy, of the variety of wigs and their different virtues, of the many benefits of hot water bottles, and such things. Not for them the melancholy wisdom of Ecclesiastes, that all is vanity. To the contrary. In their attention to detail they affirm life and the world they have in common with their past selves and with those of us who have been spared suffering such as theirs. Their stories are true to life in both senses of that expression - true in the sense of being realistic, of refusing falsification and true in the sense of fidelity. Men are seldom so faithful. We are tempted into generality and so very easily strike false notes. I suspect the courageous, humbling wisdom in this book would not have been achieved by many of the women singly. Nor would it have been achieved by them together were it not for the staff at Mercy Hospital who nourished their courage.

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**This article appeared as a review of *Women and Cancer*, Green, Genevieve (ed), Mercy Hospital, Melbourne, 1996 in *Quadrant*, March 1997. It is based on an address given at the launch of the book at Mercy Hospital for Women, Melbourne, 10th December 1996.**

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# Deliberately cloning human beings: on the significance of even contemplating it!

*Bernadette Tobin*

First, the idea that anyone would want deliberately to clone a human being was dismissed by some scientists with an airy 'who would really want to clone a human being?'[1] Next, it was said that we should consider the potential hazards and the potential benefits.[2] And then an influential scientist - the Director of the National Institutes of Health in the United States - said that perhaps after all there could be some 'exceptional' cases in which deliberately cloning human beings would be the thing to do (even though - of course - he found human cloning experiments personally offensive).[3] What will be next? News that it has already been done? The successful cloning of a sheep by Edinburgh's Roslin Institute lies behind the current interest in cloning. The scientists who cloned 'Dolly' the lamb from a cell of an adult sheep now say that researchers would be able to use the same technique to 'photocopy' humans within two years.

For what *reasons* might someone want deliberately to clone a human being? I can think of a few. By splitting embryos into twins, triplets or quadruplets, IVF doctors might implant more embryos and thus increase a woman's chance of becoming pregnant. One embryo might be implanted now and its clone stored in case another child is wanted later. Cloned copies of embryos might be stored so that, if the original child ever needed an organ transplant, the cloned embryo could be implanted into the mother who could give birth to a child whose organs would perfectly match that of the original child. One could even imagine some parents wanting to keep a frozen cloned embryo in case their child died, so that they could create a perfect replacement.

And who might be *motivated* to promote the deliberate cloning of human beings? Again I can think of a few: for instance, some scientists who out of sheer curiosity would like to do the research, some entrepreneurial doctors who would like to market new technologies, some philosophers who think that the ethical evaluation of any proposal is no more than a matter of weighing the likely benefits against the potential risks.

## Distinguishing intrinsic from instrumental reasons

How should we do the thinking about the ethics of cloning human beings? It is tempting to jump immediately to a consideration of the likely 'benefits' and 'risks', that is to say, to a consideration of the *instrumental* "justifications". Certainly such a 'balancing' of benefits and risks should be a part of our thinking and debate. But if, as a society, we are really to reflect in a disciplined and deep way about the ethics of deliberately cloning human beings, we shall need to consider a prior question, before or at least at the same time as we think about the likely consequences - for good or ill - of the proposal. We shall need to reflect on the ethics of human cloning *in itself*, whatever purposes it may be put to. That is to say, we need to think about the *character* of the proposed activity (here, deliberately cloning human beings) *in itself*, and about what the character of the proposal reveals about the kind of society that we are or want to become. We need to think of the *intrinsic* ethics of deliberately cloning human beings.

## Intrinsic ethics

What can be said about the intrinsic ethics of the proposal? I think we should begin by reflecting on how central to our sense of the preciousness of other human beings is their individuality and irreplaceability. As the philosopher Raimond Gaita has reminded us, we name human beings, we don't number them. Substituting one human being for another, replacing one with another, is unthinkable. When I love someone, I love that person in all his or her particularity. It is that individual person who is the object of my affection and well-wishing. The idea that someone else - even someone who has the same set of qualities or characteristics as my friend - could substitute as my friend is just silly. And when I wrong someone, and feel remorse for what I have done, it is that individual person who continues to live on in my mind and my heart.

## Distinguishing cloning human beings from cloning animals or plants

It is important to note that, though there may be prudential reasons for being cautious about proposals to clone animals and plants, the notions of individuality and irreplaceability do not play the same role in our thinking about animal husbandry and plant development as they do in our thinking about other human beings. So the ethical evaluation of cloning animals and plants will be a fundamentally different investigation.

## Children as replaceable commodities

Earlier I said that the idea that someone else could substitute as my friend is unthinkable. Perhaps I should have said 'ought to be unthinkable'. For at least one philosopher encourages us to think that there may be nothing wrong with 'replacing' a disabled newborn infant with another child. That is to say: there are voices in the cultural debate about this and related issues which encourage women and men to adopt a consumerist attitude to the having of children, an attitude which sets as a condition on their acceptance of the child that he or she meets their own specifications ("I want a boy, of a good height and general fitness, and I want him next year, not this, and I want to have one in reserve in case I lose him") even though they may *later* treat the child with unconditonal love and respect.

Of course, there is much more to the individuality and irreplaceability that we cherish in our children than their genetic identity: identical twins are still unique individuals. But recognition of that biological fact is no reason for dismissing questions about the ethics of deliberately cloning human beings. Rather it should be a starting point for genuinely serious reflection on the ethical issues.

Without trying to foreclose that reflection, I suggest that we will find that, as a society, we have good reasons for proscribing the deliberate cloning of human beings, *whatever the putative benefits*. And we should prohibit the cloning experiments by law, and not leave it up to individual research ethics committees to decide whether or not they will allow researchers in their institutions to conduct cloning experiments.

## The need for legislation

When the Australian Health Ethics Committee (AHEC) - the body which has the responsibility for overseeing the conduct of institutional research ethics committees in Australia - issued its new guidelines on 'assisted reproductive technology' late last year, the guidelines specified 'experiments involving human cloning' in a list of proscribed practices. In addition, recognising that its guidelines govern the conduct of only those researchers who receive funds from the National Health and Medical Research Council (NHMRC), the Committee's chairman also wrote to the Federal Minister for Health to express AHEC's unanimous conviction that uniform legislation should be introduced in each of the Australian States and Territories to regulate and monitor research and technology in this area. This recommendation was made unanimously. It is likely to be opposed not only by those scientists and medical entrepreneurs whose activities are currently completely unregulated (some of whom claim that they voluntarily abide by NHMRC guidelines) but also by others whose activities are subject only to the decisions of a local institutional ethics committee.

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[1] See for example the comments of Dr Karen Dawson, a geneticist at Monash University's Institute of Reproduction and Development, *The Australian*, 25th February, 1997

[2] Senator Stott Despoja, Letter to the Editor, *The Australian*, 26th February 1997

[3] *Sydney Morning Herald*, 8th March 1997, p 31

# The ethical evaluation of genetic modifications to human beings

*Bernadette Tobin*

A book review: *Genetic Intervention on Human Subjects*[1]

*"There is no doubt that you have a set level of happiness and that it is genetic."* Thus says Dr David Lykken, a behavioural geneticist from the University of Minnesota, agreeing with a recent study published in the journal *Psychological Science*.[2] It seems that hardly a week passes without some new and extravagant claim being made about the significance of our genes to the way we live our lives and about the changes we might bring about - to ourselves and to future generations - through genetic intervention. Since many of us find the science of molecular biology (on which the study of genetics is based) difficult to grasp, how are we to assess such claims? More importantly, how are we to think about the ethical issues raised by the new technological possibilities? At the moment our ability to diagnose genetic disorders far outstrips our ability to treat them. In some cases, there is a possibility of using knowledge gained through genetic diagnosis to make earlier and more effective treatments of some conditions though abortion is still the most common intervention offered if a foetus is found to be genetically defective. If couples have to decide how to use the genetic information they are provided with, if genetic information can be put to both good and bad uses, how are they to decide the ethics of any particular proposal?

This short book - the main essay is little more than forty pages - will be a excellent starting point for anyone with a serious interest in thinking through the ethics of human genetic engineering. Genetic Intervention on Human Subjects represents itself modestly as no more than a contribution to this debate from a Catholic perspective. It is the report of a working party of the English Catholic Bishops Joint Committee on Bioethical Issues.[3] But, with the exception of two short sections (one in the chapter entitled "Moral considerations: human beings and their fulfilment" which outlines key ideas in the Catholic-Christian tradition of thinking on respect for human life, the other an appendix of extracts from documents on disability and on clinical genetics from the Vatican), the discussion does not invoke theological concepts in reaching its conclusions. So it really ought to be understood as a contribution from a Catholic perspective in the sense that it proposes an ethical evaluation of genetic intervention which is motivated by, is at home in, but does not depend upon, Catholic theology. But more of that later.

## Contents

The structure of the book can be set out simply: It begins with a brief scientific account of gene therapy and of the some of the disorders for which it has been considered: the science here is introductory and key terms from molecular biology are explained. There follows the sketch of an ethical context for the moral evaluation of gene therapy and other genetic interventions. Then, distinguishing between therapeutic and non-therapeutic interventions, the report considers two forms of therapeutic gene therapy: therapy which is intended to target the individual person treated (*somatic therapy*) and gene therapy which in intended to target an indefinite number of people (*germ-line therapy*). Finally the book considers whether non-therapeutic genetic interventions, somatic or germ-line, could ever be justified. Why is the book so useful?

## Framework of ideas

Firstly, it sets out a clear framework of ideas within which specific proposals and particular issues may be considered. As someone who is often asked to provide just such a framework for the discussion of problems in the ethics of health care, I predict that the one set out here will help people work out reasoned answers to really practical questions. No doubt some readers will want to reject the framework itself, either in whole or in part: but even they should be grateful for the clarity of exposition of the ideas which constitute the framework.

The key ideas in the framework are:

- that that the role of medicine (or we might say "health care") is the promotion human well-being, in particular the promotion of health (and health is one of the basic human goods);
- that there are moral constraints - for example, those concerning the interests of others - on the ways in which any human good may be promoted;
- that the pursuit of health (as one thing amongst a variety things worth pursuing) is generally the responsibility of the individual whose health is at stake;
- that the responsibility for one's health includes a responsibility for one's genetic health both in so far as it affects the individual and in so far as it affects his or her descendants;
- that the responsibility for the health of one's children includes a responsibility to take reasonable steps to prevent genetic damage to one's children and even perhaps to one's remote descendants.

## The distinction between therapeutic and non-therapeutic interventions

Secondly, the book employs a distinction which ought to be assumed in any discussion of questions of medical ethics but which is often overlooked: the distinction between therapeutic and non-therapeutic interventions. A therapeutic intervention has as its goal the restoration or maintenance of health in the person or person acted on. A non-therapeutic intervention has some other purpose as its goal: for instance non-therapeutic research on human subjects may have as its goal an increase in the researcher's knowledge (whether scientific or clinical). In the case of genetic interventions, modifications which have as their purpose the enhancing of some desirable human characteristic (intelligence, or memory, or height, or sporting prowess, etc.,) are non-therapeutic: they are not aimed at the restoration of health but rather at improving the individual or individuals in whom they are introduced. A good first question to ask of any proposed or imagined genetic intervention is: is it intended to be therapeutic or not?

## Antidote to contemporary disparagement of the disabled

Third, the book provides a marvellous antidote to much of what is said these days about people with disabilities. There is a clear recognition of the human fact that the *attitudes of others* are influential in making a disability — a functional disorder — a major handicap in the society in which the disabled person lives. In view of the fact that the rights of disabled children are often threatened in discussions about prenatal diagnosis, the authors recommend that genetic counsellors be given some form of training in advocacy on behalf of the disabled. The Report goes further to suggest that it can be argued that genetic counsellors should not merely be encouraged but required to have some experience (outside a clinical context) of working with the disabled and their families.[4]

## Why enhancement should be sought in some ways and not in others

Fourth, there is a rigorous discussion of the arguments which attempt to justify perfecting an individual (or individuals) by genetic interventions (whether somatic or germ-line). The authors argue that we ought not to do this. Health, like other human goods, should be pursued by "human teleology" itself (it is better for people to be nourished by feeding themselves rather than by others putting them on feeding tubes). In addition, they argue, we do not have the same entitlement to intervene for non-therapeutic reasons on behalf of our descendants as we do on behalf of our children: this thought is suggested by the generally acknowledged idea that strangers do not have the same entitlement to modify children in non-therapeutic ways as do their parents. And even with respect to perfecting one's own children, it would be better to do this by developing their intelligence rather than by doing anything which involves controlling or manipulating them, for the latter runs close to treating children as *raw material for parents' plans* rather than as human beings in themselves.[5] The authors invite us to reflect on the fact that so many proposed as well as existing practices discourage what should be an integral feature of any parent-child relationship: an attitude according to which the child is seen as a person equal in dignity to the parents, who is to be welcomed and cared for *not as a wanted possession but for his or her own sake*. They invite us to recognise a new feature of contemporary culture, at least in the developed world: an obsessively consumerist attitude to the having of children.

## Some quibbles

By now I hope I will have made it clear that I am warmly recommending this book to anyone interested in thinking about the ethics of genetic interventions in a disciplined and deep way. Of course, such a brief discussion as is found in the book will raise as well as answer a host of questions. Much of the ground is covered very swiftly. For instance the key concept of "human teleology", even though it may have an intuitive appeal, needs more explanation than it gets here. And I was disappointed to find no explanation of the term "genome" in the Glossary though it is used in the text and is central to the authors' consideration of a possible line of argument against the permissibility of germ-line therapy.[6]

In addition, in the discussion of health as the goal of medicine, there is no specific recognition of the fact that much of what goes on in medicine has as its objective the goal of stabilising someone in what is, for that person in those circumstances, a reasonably satisfactory condition. And though I applaud the authors' rejection of the World Health Organisation's broad definition of health in terms of a very high level of psychosocial capacity, I wish they had said a bit more about their own more precise sense which refers to a more modest level of such capacity.[7] Much of the debate hangs on how one defines health.

And, I wonder whether it really does make sense to say that one is responsible for one's genetic health even in so far as it affects one's descendants.[8] Isn't the latter not so much a part of one's responsibility for one's own health as a part of one's special responsibility for the health of some others, in particular that of one's own children and by extension that of their children? Given the foundations of the proposed way of evaluating the ethics of genetic intervention in terms of the specific contribution of health care in promoting human fulfilment which is primarily the responsibility of the person whose fulfilment is at stake, this is not an idle issue.

But these are just the sorts of issues that a well-ordered discussion of the ethics of genetic modification will raise.

## From a Catholic perspective

One last thing. I said earlier that the book should be seen as a contribution from a Catholic perspective in the sense that it proposes an ethical evaluation of genetic intervention which is motivated by, is at home in, but does not depend upon, Catholic theology. There are, I think, two reasons why people who do not start from a Catholic perspective on ethical issues will find the report intellectually informative and challenging. First, Catholics claim that the morality they endorse is sound morality, the challenges and obligations of which can be appreciated by anyone of goodwill. A Catholic perspective on a moral question does not rely on religious presuppositions: rather it invokes a certain understanding of some key ideas in the philosophy of morality (for instance: what kind of being is a human being, what constitutes human flourishing or well-being, what is the role of moral principles and moral constraints, what is the character of moral judgments or decisions). Of course, to this moral philosophy is added a Christian dimension, the idea that life is a gift from God and that all human beings are called to the same destiny of a life with God. But in principle this dimension does not change the substance of the morality found in Christianity.

Secondly, the book offers the kind of contribution to our thinking about human genetic engineering for which so many people express both a need and a desire: an attempt to provide an *ethical context* within which we can think carefully and deeply about these questions. The discussion of this ethical context (the framework of ideas to which I have already referred) is brief (readers are alerted to references which elaborate the ideas and consider objections to them) but accessible: it serves as a excellent starting point for consideration of a range of questions about human genetics.

## Conclusion

Most discussions of the ethics of genetic interventions on human beings focus on the likely risks (or safety) of such procedures and thus on the necessity for the prospective patient to be provided with sound information about any proposed form of genetic modification, and thus on the difficulties in stating clearly what constitutes the giving of informed consent to any proposed genetic modification.

This book cuts much deeper. The authors recognise that germ-line therapy may not be found to be worth pursuing in a society in which it is thought appropriate to eliminate *disease* by eliminating affected *individuals*. They recognise that, because it is simpler and easier, embryo selection is more likely to become common practice than is therapy on embryos or gametes. None the less they provide a principled way of evaluating the whole range of genetic interventions on human beings regardless of whether they will ever become reality. In the course of doing that, they reveal how just how silly are claims of the kind with which we began: that you have a set level of happiness and it is genetic!

## References

1 *Genetic Intervention on Human Subjects: The Report of a Working Party of the Catholic Bishops' Joint Committee on Bioethical Issues*, London, 1996 (Distributed by The Linacre Centre, 60 Grove End Road, London, NS8 9NH)

2 As quoted in "True Happiness Is in the Genes", *Sydney Morning Herald*, 12 February, 1997

3 Amongst those whow help is acknowledged is Dr Anthony Fisher OP of Australian Catholic University!

4 pp. 26-27

5 This last idea runs against the consequentialist strain in our culture according to which alternative means to the same end are in principle morally equivalent.

6 pp. 31-32

7 p. 22

8 p. 24

Copies of *Genetic Intervention on Human Subjects: The Report of a Working Party of the Catholic Bishops' Joint Committee on Bioethical Issues*, London, 1996 are available from the John Plunkett Centre, St Vincent's Hospital, Darlinghurst, NSW, 2010 at a cost of $15.00 (including postage). Cheques should be made payable to the John Plunkett Centre.

## Notes on the Centre

The Plunkett Centre is pleased to announce the success of its application for an Australian Postgraduate Award (Industry). These awards are made - on a competitive basis - by the Australian Research Council. They enable a University (in this case, Australian Catholic University), in collaboration with an industry (in this case, the Anxieties Disorders Clinic at St Vincent's Hospital) to conduct research into a specific topic of joint interest.

Mr Charles Naylor has been awarded an Australian Postgraduate Award to undertake the research and thereby to enrol in the degree of PhD. Charles recently graduated from the University of Sydney where he completed an Honours Degree in Philosophy with First Class Honours. He was an exceptional student who was awarded the John Anderson prize for the best work in fourth year philosophy.

Charles' research project is entitled "philosophical and ethical issues in the allocation of health care resources, with special reference to the treatment of schizophrenia: hearing the voice of the community." His research is to be supervised by Dr Bernadette Tobin and Dr Anthony Fisher of Australian Catholic University and by Professor Gavin Andrews of the Anxiety Disorders Clinic at St Vincents Hospital.

### Linacre Centre for Health Care Ethics International Conference
### "Issues for a Catholic Bioethic"
### Queens' College Cambridge
### 28 - 31 July 1997

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### Australian Bioethics Association Fifth National Conference
### Melbourne 1997
### 3 - 6 April

International House
The University of Melbourne
241 Royal Parade
Parkville VIC

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# The Euthanasia Debate — Taking stock

*Gerald Gleeson*

Now that a second death[1] has occurred under the provisions of the Northern Territory's Rights of the Terminally Ill legislation, the euthanasia debate enters a new phase in which it begins to seem intractable. But since this debate needs to continue, it may be helpful to take stock of the sides and the issues.

Advocates of legalised euthanasia fall into two groups: (1) those who believe we should be allowed to take control of our own destinies, to chose when and how we die, if necessary by an act of deliberate killing, and (2) those who believe that, even if euthanasia is probably a bad thing in general, there should be legal access to it for those who want it.

Opponents of legalised euthanasia also fall into two groups: (1) those who believe we should never kill innocent fellow human beings, no matter what the circumstances, and (2) those who believe that, even if deliberate killing might be defensible in rare cases, legalised euthanasia would be too easily abused and would inevitably lead to non-voluntary euthanasia (i.e hastening death without a patient's consent).

The pressing question for us as a society is about what to do in the face of such opposing positions. Because we privilege individual freedom so highly, the most appealing option would seem to be that of keeping the law keep right out of the issue, either by its turning a blind eye — as happens in the Netherlands, or by legalising euthanasia — as has been done in the Northern Territory. I call this the most appealing option because it sits so easily with the secular liberalism of western democracies. It leaves the decision up to the conscience of the individual. It treats euthanasia as a private matter which involves no harm to others. It keeps the state and its laws "morally neutral", with contentious ethical issues solely in the hands of individual citizens.

From this liberal perspective, the opponents of legalised euthanasia are said to be imposing their moral convictions on others; they are heartless and inhumane, condemning the terminally ill to needless suffering whether for religious or other reasons. From the liberal perspective, the "burden of proof" in this debate lies squarely on those who insist on outlawing euthanasia. The more polarised the debate becomes, the more appealing the liberal option can appear.

Yet, despite it obvious appeal, I believe the liberal solution is short sighted and that it avoids the deeper issues at stake for us as a society. Without arguing the case against legalised euthanasia in detail, I want to note some of the reasons why the "burden of proof" remains where it always has been, on the advocates of a change to the existing law.

1. Euthanasia is not just an issue for individual conscience because a person's death is never a purely private matter, and in any case the request for euthanasia is a request for someone else to kill or to assist in killing. To legalise euthanasia would be to legalise, not suicide, but the practice of killing some members of our society.

2. Legalised euthanasia would alter fundamentally the relationship between doctor and patient. That relationship is defined by the goods of health which the practice of medicine serves — the cure, alleviation or palliation of the sick person. The burden of proof lies on those who claim that allowing doctors to take life would not undermine the very basis of their profession.

3. Legalised euthanasia does not ensure the moral neutrality of the state. The law is always an instrument and an expression both of public policy and of the shared values which hold a society together.

Present Australian law (apart from the Northern Territory) embodies the values which have shaped western civilisation – above all the protection of innocent human life, regardless of its "quality". To change that law would be to endorse not only freedom of choice, but also the precise choice that would be permitted, namely the choice to kill the innocent. The burden of proof lies on those who claim that such a change would not compromise the protection of the most vulnerable among us.

4. Legalised euthanasia would not necessarily ensure compassion and dignity for the dying. It would probably make many terminally ill people more fearful than they are at present. Moreover, the process of dying is rarely "dignified" – it necessarily involves the breakdown of physical and mental systems and many "undignified" moments. But embarrassing moments do not compromise the absolute worth and dignity of the person. To accompany the dying person and assure them of their worth despite their physical or mental deterioration is, arguably, the most powerful expression of our respect for personal dignity.

5. To be human is to be responsible for finding and creating meaning and value in one's life and in one's relationships, and this quest for meaning is intensified as one's life draws to an end. While a person lives it is always possible for them to find further significance in their life. This is why the key to the tragedy of human death is its finality. Legalising euthanasia means accepting that someone's decision today is their decision forever. Yet it is an open question whether it really is compassionate to cut someone's life short, to deny him or her the possibility of change, of further reflection and consideration, of fresh attitudes and decisions, of deepened relationships. (The Northern Territory legislation allows life to be ended up to twelve months ahead of when death is anticipated!)

6. Finally, the primacy of freedom of choice must itself be questioned. Liberalism has many critics at present, who are in various ways concerned about the "emptiness" of the theory, since choice presupposes that things other than choice really do matter. These critics highlight the more fundamental question of what our freedom is for? As philosopher Charles Taylor has remarked, "unless some options are more significant than others, the very idea of self-choice falls into triviality". Much as we should respect a person's autonomous choice, even the choice for euthanasia, we may not avoid asking whether it is a wise or right choice, a choice that furthers the goods of human living, a choice we should encourage others also to make. That is to say, we may not avoid asking whether deliberately ending someone's life really is the right way to assist him or her in dying. The appealing liberal option simply ignores this question, in the naive hope that we can remain a humane society without having publicly to address the difficult questions of meaning and value which shape our lives together.

The euthanasia debate turns upon fundamental ethical issues which are too important for us to allow this debate to become intractable, too important for us to allow ourselves to settle for the minimalist "liberal" solution. Contrary to popular perception, the "burden of proof" in this debate remains on those who would legalise euthanasia. But far from discharging that burden, the advocates of legalised euthanasia have, at best, tried to circumvent it by the simplistic appeal to personal autonomy.

What matters most for terminally ill patients, I suggest, is that we neither abandon them nor accede to the belief that their life is no longer worth living and/or that they are simply a burden to us. The self-understanding with which a person dies remains fixed forever. To accede to a request for death to be hastened, even a seemingly calm and considered request, is arguably to do what no human being ought ever do – to become an instrument of finality as to the significance of another's life.

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**[1] This article originally appeared in *The Sydney Morning Herald*, 7 January, 1997.**

# NOTEBOOK

Fourth Annual

## INTENSIVE BIOETHICS COURSE

### A "virtues" approach to the ethics of health care

A "virtues" approach is one which will help health care professionals deal with the difficulties and dilemmas of everyday practice

To be conducted over four evenings
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The Auditorium, The "New" Building, Australian Catholic University,
179 Albert Road, Strathfield

Wednesday, 23rd April 1997
Wednesday 30th April 1997
Wednesday 7th May 1997
Wednesday 14th May 1997

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| *23rd April* | ◆ An introduction to ethical inquiry in general and the ethics of health care in particular - virtues-based ethics as a response to moral disagreement | Dr Bernadette Tobin<br>Dr Gerald Gleeson<br>(John Plunkett Centre for Ethics) |
| *30th April* | ◆ Tension between the pursuit of the proper goals of health care and the respect for patient autonomy - informed consent, withdrawal of treatment, euthanasia and other end of life decisions | Mr John Quilter<br>Mr Keith Joseph<br>(John Plunkett Centre for Ethics) |
| *7th May* | ◆ The ethics of research involving human subjects - philosophical principles, trustworthy research and the role of institutional ethics committees | Dr Martin Kelly (St Vincent's Hospital)<br>Dr John Watson (University of Sydney) |
| *14th May* | ◆ Social justice and health care - the ethics of resource allocation, with particular attention to the care of the aged and the mentally ill | Dr Anthony Fisher<br>(Australian Catholic University) |

The Intensive Bioethics Course may satisfy part of the requirements for the Graduate Certificate in Bioethics (Health Care) at Australian Catholic University or satisfy a bridging requirement for admission into the Master of Arts in Ethics (Health Care).

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