Matters of Living and Dying – Some Ethical Considerations

by

Dr. Davis McCaughey

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The Chairman of the meeting was Dr. John Emmerson Q.C.

The preparation of this talk has gone full circle. When Dr. Silver invited me he suggested that I should here say some of the things which I said at the Dean of Medicine's Seminar on 'A Better Death', in the University of Melbourne in July last year. My brief paper was entitled 'The Right to Die?' It was a brief paper in which I tried to delineate some of the ethical considerations as distinct from the legal parameters within which doctors may assist patients to a better death.

I had the impression, however, that simply to repeat what I said on that occasion would be too brief, not fully enough argued for this occasion. You would, I rather gathered, expect something more than a fifteen-minute introductory paper, apt though that may perhaps have been for an occasion when I was followed by other speakers. All those papers will shortly be published in Chiron, the journal of the University of Melbourne Medical Society.

What became apparent to me on that and on other occasions was that ethical questions are of a distinct character, and that their determination has to be arrived at in a distinctive manner. Not separable from medical considerations or legal procedures, but distinguishable from both. So in the last few days I wrote rather a long paper on the distinctive character of good ethical discussion on medical matters. It was a bit too long, and I was dissatisfied with it; but thought that I could abbreviate it this morning.

Then today I pick up The Age, and read across the front page 'In an open letter to Jeffrey Kennett, seven Melbourne doctors say they are - [in large letters] Helping Patients to Die.' Maybe, after all, I should follow Dr. Silver's original suggestion, discuss the ethical questions involved in the claim that there is a right to determine the time of our own deaths, and those of other people. I should do so fairly briefly, and listen to the comments of medical practitioners and lawyers on this important theme.

So I abandoned the paper which I had written - which might in any case have been measured by so many yawns a minute - and I shall try to make some introductory remarks on this current theme. I shall not repeat exactly what I said in the Dean's Seminar at the University of Melbourne, but I shall stick to that one issue which was summarised for me under the title 'The Right to Die?'

Let me mention some considerations which must be borne in mind as we proceed with the discussion of this topic:

1. One danger about discussing almost any issue in terms of rights is that it unduly focuses attention on the individual. The juxtaposition of the individual and the society of which he or she is a part is rarely clearer than at the point of death. It is true that for the most part we die as individuals. The phrase 'the right to die' certainly focuses attention on the individual man, woman or child who is dying. But death when it occurs is not adequately explained in those terms. Every death has its social context - some perhaps more dramatically than others.

We have brought death, like being born, into an area in which we can exercise some degree of control over the manner of its occurrence. The point is engagingly made by Gordon Dunstan, the outstanding moral theologian in England who has given attention to medical ethical matters in recent decades. He opens an essay 'The presumption in favour of life' with the following paragraph:

> No creature living asked to be born. Every living creature seems instinctively moved to stay alive. All living creatures are genetically primed to transmit life, to propagate their kind. All living creatures die. Man is one of these living creatures. All these four statements are as true of him as of them.
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> Yet man in his moral rationality, that is through his capacity for choice, has subordinated to ethics two of these instinctual drives, the instinct to survive and the instinct to propagate his kind. We have fortified the instinct for life with amoral presumption in favour of life. [1]

Or again a little later: 'From the biological urge to live we have moved to a moral and legal presumption in favour of life.'

The presumption guiding doctors is that they work for health and combat disease, that their primary interest is in the preservation of life and not in the hastening of death. That presumption will to some degree have been called in question, or be thought to be called in question by the viewpoint expressed in the letter of seven doctors addressed to the premier. They want the law changed which prohibits assisted suicide. My chief interest is to ask how we react to their plea, morally or ethically.

At the time when I was preparing my talk for the Dean's seminar I was much moved by the death of a relatively young man known to me. Almost exactly a fortnight previously there had died in England a man of 53 years of age who had had a distinguished career in the Royal Air Force and had just taken up an appointment with immense responsibilities for defence with the European Community. On a brief return to England - it may have been in the middle of giving a lecture - he suffered a massive stroke, which rendered him deeply unconscious.

After the customary and appropriate medical attention, it became clear that he was not going to recover the use of his facilities; and it was agreed that if the doctors were convinced that he had suffered irreparable brain damage so that brain death could be diagnosed, he should be taken off life support systems and permitted to die peacefully. His family accepted this. Before the support systems were removed, however, his immediate family, his wife and two daughters, his mother, his brothers and sisters (for he was a member of a large family of siblings) went to the hospital as it were, to say goodbye.

A week later that small intimate group, supplemented by others, gathered for the funeral service: an occasion when they would grieve together, be comforted by their memories, thanksgivings and proper pride in his achievements, by their common love and hope. A month or two later, probably in September, the RAF held a Service in the Church in London customarily used by that Service on such occasion: then his colleagues and indeed the nation could express their sense of loss and gratitude for what he had been and done. For no one concerned will life be quite the same again.

Every death has its social context - this one perhaps more dramatically so than many others. 'Naked came I from my mother's womb, and naked shall I return' cried Job. These words have sometimes been used to provide comfort to the dying, suggesting the cycle of life is over; but in the original poem this was an expression of horror. Job had been deprived of all the things that make life rich and tolerable - possessions, wife and family - stripped naked he now stood alone.

We have our own ways of stripping people naked, in life and in death. We remove them from their homes, to be born or die in hospital - and we do not seem to care how far from home that hospital may be, only to be sure that the patient does not stay there too long (often not long enough to establish some relationship of trust with the doctors and nurses), as short as possible in order to obtain maximum financial benefit for the institution.

So modern individualism would deprive us of those relationships which make life meaningful; and talk of the right to die isolates the individual, puts him or her where they cannot be, at the single determining centre of their own deaths, a position which could never be sustained in life, which indeed denies some of the most important characteristics of their lives.

> 'No man is an *Iland*, intire of it selfe; every man is a peece of the *Continent*, a part of the *maine*; if a *Clod* bee washed away by the *Sea, Europe is* the lesse, as well as if a *Promontorie* were, as well as if a *Mannor* of *thy friends* or of *thine owne* were; any mans *death* diminishes *me*, because I am involved in *Mankinde'*

John Donne writing before modern individualism has gained its full force knew better.

Every culture and religion has rites wherewith it rescues the death of the individual from that ultimate loneliness; and increasingly the treatment of the dying involves the co-operation, acceptance on the part of the patient (where that is possible), the understanding on the part of the family, and of carers (an increasingly important role in our society), and the responsibility which comes from special knowledge exercised by the doctor.

It may be that we have no rights either to death or to life: the state, the condition is given us. But we, as members of the human race, have some say over the manner of our living and of our dying, the doctor especially so.

2. We move now to the specific question of intervention.

The invitation to intervene or to withdraw treatment - to make that choice about the manner of our living or dying - is a moral decision made by an individual or by his or her proxy, but it is always an invitation to another morally responsible person, the doctor, or series of persons, the medical staff, doctors, nurses, perhaps others, to whose care the patient has been or will be committed. A responsibility then falls upon the doctor or nurse, perhaps in intensive care, towards the patient who inevitably will die some day somewhere, and perhaps will almost certainly die of this sickness if left alone? How are limits set to the obligation to preserve life? When is the prolongation of life no

longer a professional duty? Should the doctor be under an obligation to observe the wishes of the patient to assist a speedy end to his or her suffering, weakness, and life?

In the immense literature to which such questions, and other like questions, have given rise, it has become increasingly important to ask not only what has been called the vulgar sociology of knowledge question, 'who is saying that and from what background?' but the related question, 'for whom is this written? Who is the implied audience? For whom will this writing be helpful, in all the agonising dilemmas of life and death?'

Out of a slim acquaintance with the literature let me try to illustrate this point by referring, at the risk of caricature, to three authors. In each case the primary audience as it were spills over into a wider audience. It is as though, while addressing one group they expect others to be eavesdropping, listening in.

I begin with Karl Barth, probably the towering Protestant theologian of the 20th century. In his Church Dogmatics[2] he writes for those who share his faith in the triune God of the Christian creed. He discusses capital punishment, euthanasia, abortion and a number of other issues, in the volumes on the doctrine of creation. The God with whom we have to do is at once the gracious God whom we know in Christ and is the Creator who gave men and women life, to be exercised in freedom, life which is to be protected. 'Human life – one's own and that of others - belongs to God'.

His argument about 'euthanasia' is clearly influenced by his concern for the weak. 'No community, whether family, village or state, is really strong if it will not carry its weak and even its very weakest members. A community which regards and treats its weak members as a hindrance, and even proceeds to their extermination, is on the verge of collapse'. The shadow of Nazi Germany falls heavily across these pages, as indeed it does across all our discussion of the termination of life, or experimentation on life, in these closing years of the century. Barth is aware, however, of the acute problems raised by modern medicine, its advances in technology and in pharmacy. He is nevertheless cautious to a high degree about encouraging patients, their families and friends, their medical advisers and attendants, and warns against taking the prerogative over life and death out of the hands of God. Then he adds,

> Yet in this connexion the question also arises whether this kind of artificial prolongation of life does not amount to human arrogance in the opposite direction, whether the fulfilment of medical duty does not threaten to become fanaticism, reason folly, and the required assisting of human life a forbidden torturing of it. A case is at least conceivable in which a doctor might have to recoil from this prolongation of life no less than from its arbitrary shortening (p. 427).

Barth adds that 'we must await further developments in this sphere to get a clear general picture'. Barth was writing in the early 1950s, and further developments certainly have taken place, sometimes promising but not always providing a clear general picture.

What is of interest in that passage, however, is its use of terms: 'arrogance', 'fanaticism', 'folly', 'torture'. These are not legal terms. Barth speaks not of how a patient or a doctor will appear before the law, but of how he or she will appear before God (coram deo, as Luther would have put it). Nevertheless, and this is the spill over, his concern is with the humanum, what belongs to a proper humanity.

I turn now to Gordon Dunstan, the Anglican moral theologian. If Barth begins by addressing his fellow-believers, Dunstan's primary audience is frequently the medical profession; and very frequently he writes in response to the questions which they raise. In his article of 1985 'Hard Questions in Intensive Care' he reproduces answers given at a meeting of the Intensive Care Society.[3]

He starts from a number of important distinctions presumably acceptable to his specialist audience, though he admits the difficulties of such summaries:

> Doctors give the moralist no rest. Just when he has managed to get some distinctions clear and to discern an acceptable working rule, the doctors find new distinctions and the moralist has to start again.

This is as it should be. Aristotle would approve. Every discipline has its own characteristics, and only when they are known and understood do the ethical questions emerge and become ready for discussion. The questions become progressively more difficult as we move through the distinctions, summarised (I hope without distortion) as follows:

i. Brain-stem death, where permission to withdraw active treatment and use organs for grafting is clear. The only problem here is an emotional one. The beating heart has for so long been thought of as the sign of life, that relatives may have to be dealt with sensitively, in particular in relation to use of organs for grafting.

ii. A little more difficult, where the patient is in a deeply unconscious state deemed to be beyond recovery, or in a persistent vegetative state: 'clinical experience and mounting statistical data point to a high improbability of recovery, but there is no certainty'. Here it is possible, indeed probable, that a distinction strongly represented in the tradition of thought about morals might be drawn upon: that between ordinary and extraordinary means of therapy. This distinction going back at least to Aquinas was reaffirmed by Pius XII in discussion with Roman Catholic anaesthetists in 1957.
Elsewhere Dunstan clarifies, what that distinction means (and does not mean). The physician is not required to use extraordinary means in such circumstances, but how define what is extraordinary? Not because of its novelty or intricacy, but because of it being not self-evidently apt to the condition and overall interest of a particular patient, as determined by a comprehensive clinical assessment (Dunstan 1988, P 79).

iii. A third category raises far more difficult questions: cases where survival of a sort is probable and where the patient or his or her proxy expressed the view that no treatment save for the alleviation of pain or diminution of distress is desired. Here, in Dunstan's view the responsibility of the doctor is paramount. In this case two different circumstances are envisaged. Where the patient himself or herself makes the request, that act must be seen in the setting of our understanding of the importance of consent. Patient consent is required to permit medical intervention. In this case consent has not been given. 'It would seem, therefore', writes Dunstan, 'that if a conscious patient, in full possession of his rationality, and in full awareness of the consequences, asks for the withdrawal of active therapy, his wish may be respected'. He goes on, however, to discuss the second case:

> With a proxy request for this from a patient's relatives the doctor has another problem. Clearly the doctor's duty is to his patient, and he cannot surrender his own professional

> autonomy; he cannot allow himself to become an agent of anyone else in any way adverse to his patient's interest. It would follow that the doctor has to judge whether the relatives' request did or did not accord, first with the wish of the patient truly expressed while conscious and rational, and secondly with his own estimate of the patient's true interest - or whether its intent or motive was other. He must then decide himself whether to accede to it or not. (Dunstan Anaesthesia, p.482).

The grounds for all this are worked out by Dunstan in the article from which we have already quoted, 'The presumption in favour of life'. He uses the word presumption as it is used in law; a man or woman is presumed innocent until proved guilty. The doctor or nurse is committed by this presumption in favour of life, to use science and skill to preserve and enhance life, unless a case can be proved to the contrary. At no point are they authorised, not even by the patient, to kill, for that would undermine the presumption in favour of life. On the other hand 'they are under no strict or absolute duty always to prolong life, regardless of other considerations'.

In that article Dunstan discusses the implications of this approach in relation to the pre-embryo and the protection due at that stage of developing life, to abortion, and to neo-natal intensive care. He accepts the distinction between killing and allowing to die, and develops the distinction between ordinary and extraordinary types of therapy. Doctors and nurses are not required to do everything they could do, only what is apt to a particular case, which may be described quite simply as management apt to the patient's condition. Curare as well as sanare, to care as well as to heal. We may recall Paul Ramsey's view that in care of the dying, care is not recourse to pretended remedies: it is comfort and company. In a final section Dunstan applies this presumption and its possible rebuttal to the questions of assisted suicide and painless killing on request. In each case he finds against the rebuttal and for the presumption in favour of life.

After looking briefly at the case of brain-damaged victims of accident, Dunstan sums up: -

> Given the principles touched on in this lecture - of a presumption in favour of life which does not entail a strict or absolute duty to prolong it at all costs, and the principles of double effect and of ordinary extraordinary means, which

> together enable the doctor, within this context, to meet the demands of necessity - the doctor is well furnished (given the necessary skills and resources) to meet the clinical demands made in the transition from an interest in living to an interest in dying well.

He lays the responsibility for clinical decisions firmly on the doctor's shoulders; but the decisions are not only clinical in the narrower sense of the word. What is apt for the patient certainly includes but is not exhausted by what is medically appropriate. In his last phrase he touches the nub of the question: how to make, and help others to make, the transition from living as well as possible to dying well, with what dignity and in as great a degree of peace and sense of fulfilment as may be possible.

Reference to dying with a sense of fulfilment brings us finally, but only allusively, to Ronald Dworkin's substantial book, Life's Dominion: an argument about abortion and euthanasia.[4] His primary audience is the deeply divided communities in the USA and in Europe over these issues. He is concerned with how varying assumptions, arguments based on different premises are used as the basis of judgements, determinations, in courts of law. His interest however goes beyond that, to a concern that community attitudes should reflect - whether stated in religious or secular terms - an awareness of the sacredness, or inviolability of life. In doing so the community will be recognising a deeply felt conviction of many people who may differ in its application in relation to either abortion or euthanasia, when they find it easier to argue in terms of rights, of interests, of justice.

Yet reverence for life, the notion that something is intrinsically precious runs through our attitudes to many things despite the strong utilitarianism of modern life. Learning, the pursuit of truth for its own sake is essential to the life of the University.

A work of art does not gain its value from the number of dollars Alan Bond was prepared to pay for it. The care for endangered species is not justified on the grounds that we need elephants in order to use their tusks for ivory to satisfy our aesthetic or commercial interests. The lives of generations yet unborn are of intrinsic importance, and for that reason we know that we should not squander the earth's resources, however little we do about it in practice. So, as for Barth and Dunstan, life for Dworkin is a gift to be cherished.

Threatening this gift, and finally finishing it is death; and because of what life is, not mere existence but as one distinguished author put it

succinctly 'more', it matters how it comes to me and to others. When I see on television children in Somalia deprived of the means to remain alive, that is a tragedy, a waste - literally a wasting away: 'tragedy' and 'waste' two words much used by Dworkin. Similarly when I see young or elderly people in a degenerative state, in a permanent degenerative state, that is a violation, a desecration of the sacred gift of life.

It is a platitude (writes Dworkin) that we live our whole lives in the shadow of death; it is also true that we die in the shadow of our whole lives. Death's central horror is oblivion - the terrifying, absolute, dying of the light. But oblivion is not all there is to death; if it were, people would not worry so much about whether their technical, biological lives continue after they have become unconscious and the void has begun, after the light is already dead forever.

Death has dominion because it is not only the start of nothing but the end of everything, and how we think and talk about dying - the emphasis we put on dying with "dignity" - shows how important it is that life ends appropriately that death keeps faith with the way we want to have lived.

The notion of an appropriate way to die runs all through literature. Abraham, we are told, 'breathed his last and died in a good old age, an old man and full of years, and was gathered to his people'. Mr. Gladstone craved three boons of God, 'over and above all the bounty which surrounds me'.[5]

The first was 'escape into retirement'; the second, 'that I may speedily be enabled to divest myself of everything resembling wealth'; the third 'that when God calls me, he may call me speedily. To die in Church appears to be a great euthanasia, but not at a time to disturb worshippers.'

'We die in the shadow of our whole lives', says Dworkin. The stories of ruthless slaughter in the 20th Century wars and by totalitarian regimes broke that nexus between death and life. The manner of our dying may break the nexus between our dying and our living. The fear of an inappropriate death, one which has no resemblance or continuity with what we have been - our relation with, our recognition of friends and family, our capacity to reason or to pray - haunts us all. In the closing sections of his book Dworkin discusses this in relation to our sense of dignity.

It is perhaps easier to see what he is talking about when we look at the negative: 'people have a right not to suffer indignity, not to be treated in ways that in their culture or community are understood

as showing disrespect. Every civilised society has standards and conventions defining those indignities, and these differ from place to place and time to time'. Dignity, positively, means recognising the inherent value of our lives and those of others.

To dignity is linked freedom, the capacity of men and women to make decisions on their own behalf, important decisions which constitute their very being. Thus in the discussion about euthanasia both sides appeal to dignity. One believes that intervention in the process of dying, assisting it on its way, constitutes a violation of the dignity which belongs to a man or a woman.

The other believes that 'people who want an early, peaceful death for themselves or their relatives are not rejecting or denigrating the sanctity of life; on the contrary, they believe that a quicker death shows more respect for life than a protracted one' (p. 238).

These, like a number of other differences which he has described so carefully throughout his book are (I quote) "honourable convictions, and those who have them must live and die in their light .... The greatest insult to the sanctity of life is indifference or laziness in the face of its complexity" (p. 240).

Dworkin's very last chapter deals with the acutely painful cases of people suffering from Alzheimer's disease. He calls it 'Life past reason'. That and motor neurone disease raise questions at least as acute as the cases of long-term unconscious patients and those in a vegetative state or those suffering from cancer which seem to receive more attention in the literature. Here in a most distressing way the dignity of living seems to be removed in the process of dying.

Dworkin, lawyer though he is, stops short of providing 'any detailed legal scheme for deciding where doctors may hasten the death of patients who understandably want to die or of unconscious patients who cannot make that choice' (p. 216). He does however issue some sobering warnings. I quote two:

> ...the initial question is whether a decent society will choose coercion or responsibility, whether it will seek to impose a collective judgement on matters of the most profound spiritual character on everyone, or whether it will allow and ask its citizens to make the most central personality-defining judgements about their lives for themselves. (p. 216).

Or again:

> Making someone die in a way that others approve, but he [or she] believes a horrifying contradiction of his [or her] life, is a devastating, odious form of tyranny.

Freedom is an essential part of the dominion of life. Freedom is an essential mark of our dignity. It is one of the great characteristics of the English law (which we have inherited) that it does not set out to make us good, or make our decisions for us, but to protect our freedom. If this conclusion is somewhat at variance with some positions that might be thought to flow from some earlier parts of this paper, so be it. Only by way of tension shall we have growth in understanding.

If as a layman from both your professions that of medicine and that of the law I must declare myself on the present controversy, but assuming that I may do so as a citizen, it would (I think) be in two assertions. First, let the law be amended so that the doctor is free from the threat of criminal charges if he or she has been acting in the best interests of the patient. Let the law protect but not too readily intervene in the freedom of the doctor-patient relationship. Second, let the profession itself (with the consultation with members of other professions in which it customarily engages in such instances) lay down the guidelines which doctors should observe in dealing with the terminally sick or distressed. Do not encourage legislatures to undertake detailed definition in such matters.

I am aware that that is easily said. To implement will be far from simple.

END NOTES

1. New prospects for Medicine ed. Jonathan M. Austyn, p. 71 (OUP 1988)
2. Carl Barth Church Dogmatics Vol. IV 'The Doctrine of Creation 4' pp. 397-470, the section on the Protection of Life, Eng. trans. (T&T Clark, Edinburgh 1960)
3. Anaesthesia 40, 1985: 479-482
4. Ronald Dworkin Ulife's Dominion (Harper Collins, London 1993)
5. Philip Magnus, Gladstone p. 256, (London 1968 ed).