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Guest Editorial

EUTHANASIA :

can we make sense of the issues?

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From being for all purposes a taboo subject until a few years ago, euthanasia has suddenly leapt centre stage. With the Cox case and the Northern Territories Bill at one extreme, and opinion polls and chat shows at the other, views usually reserved for private discussion or dusty bookshelves have been brought into the limelight. Its not surprising that, like actors in the first few nights of a new production, the lines we find ourselves using sometimes seem a little crude and under-rehearsed. It seems time to take stock and look widely through the ideas which lie behind the debate, because of course it is not as new as it appears.

Perhaps the first question is why this should all be so important *now*? Certainly it owes a lot to the different ways in which we now look at health and health care - everybody's business, rather than just what the doctor orders. For a long time, even medical ethics has been dazzled by the brilliance of new technology. It has taken us a little time to wake up to some of the worries within us. To my parents certainly the main fear was not of death, but of being kept alive past their time, perhaps dotty or undignified - part fantasy, but for those visiting the long stay wards, as they did, by no means entirely so. Pressures as disparate as the current youth and fitness culture, governments panicked by high health care expenditure, and the gradual fading of firm religious beliefs in western countries, must all play their part in creating current perplexity.

This is not helped by some paradoxes within health care. For instance, public health policy suggests that sudden death is a tragedy which should be prevented (we should all become good at resuscitation); yet most people are just like my parents in wanting such a quick and decent end. They would acknowledge that the quality of life has improved overall in recent years, but the quality of *dying*, with notable exceptions, has not. (If dying at home amongst your own folk is a criterion, the shift to hospital deaths makes this deterioration a plain fact.) More and more we expect to be able to make our own choices in health care, including whether to become a 'patient' at all; but autonomous choice seems to stop short of the final one. People who want to talk to their clinical attendants about an assisted death will find that the professionals don't like to talk about it at all. Those attendants who do actively respond to the patient's wishes, are liable, like British rheumatologist Nigel Cox, to find themselves facing prosecution. In the words of the old Goon show, 'its all rather confusing really'.

What we shouldn't be confused about, though, is what the words mean. Although actually coming from a Greek construction meaning just 'good death' - who could argue against that? - the term euthanasia now implies release from a death which would be considered, or threaten to be, unpleasant in some way - painful, prolonged, undignified or perhaps even far too long in coming. Someone else is assumed to be involved in some way, thus distinguishing it from suicide.

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The awful events in the death camps of Eastern Europe in the second World War remind us of the crucial difference between an *involuntary*, or forced death, and a fully *voluntary* understood and requested process, (though we shall need to examine how that distinction might be maintained in practice). Also, distinctions have to be made between *passive* euthanasia, where treatment or support is withdrawn, and *active* intervention. The former now seems hard to oppose, even though the obsession with health care in the United States is such that there is still debate there as to whether patients may end their treatment. Most legal systems and most ethical thinking see this the other way round:

that a clinician continuing to treat a patient against her will is, in some senses, committing an assault. However problematic stopping treatment may be for professionals or relatives, a person who chooses to die by coming out of a treatment programme, or by stopping essential maintenance (like insulin) is acting within her rights. That this death will often not be pleasant, fuels the request for active euthanasia, but does not blur the distinction.

But if such request is to be accepted as voluntary, it must be made by someone who is consenting - that is who is informed and *competent* to make the request. Here shades of doubt come in. Everyone knows what having an appendix out is, and anyway if you're not sure you can talk to someone who's had the operation. Voluntary euthanasia is obviously different, and is most important to just those whose competence might be questioned. People worried about dementing might be doing just exactly that, while people dying from any disease are also likely to be depressed, particularly if they are facing up to the sort of future which makes them wish to speed their death. Both conditions have caused people to question the competence of sufferers. We shall return to the dementia issue, but we should look depression in the face. It is likely to be essentially a normal though deep sadness at what is having to be faced. Normal clinical practice elsewhere would respond with treatment but would not question the

competence of someone who is depressed, unless it is extreme: so why here?

Listening sympathetically to the requests of people who are dying, and at the same time dealing with all their symptoms, physical and mental, to the best of our ability, comprise together the only possible moral response. Yet high standard terminal care and euthanasia are often seen to be in some way mutually exclusive or antipathetic, as if more of the latter

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would damage the former. Recent experience in talking to dying patients, suggests the reverse; that open discussion between dying patients and unhurried but involved clinicians, is likely to bring out more *requests* for assisted death. However, in the best hands, terminal care is such that the likelihood of needing to put such a request into practice is very low. Most people will be able to die well without the resort to euthanasia. Failure of symptom control is not common. However, contrary to what some hospice doctors maintain, such cases certainly exist. What also does exist, but is common, is fear of a poor or painful death. This is fueled by professional reluctance to discuss the issue, and by the knowledge that in most places, the law refuses to countenance an active response from a clinician.

Looking then at the request from a competent patient who is dying, for the end of their life to be brought forward by some active intervention, we need to consider a framework for our thinking. Kierkegaard suggests that philosophy is like sewing, we need to knot the end of the thread. Where then are we to anchor this debate? First, I would suggest, in some clear *values*. We should all probably agree that *human dignity* is essential to our view of good life. Also, *professional integrity* is key to this debate. Between these two, lies the understanding that clinicians are there to *serve* people and to *respond* to their real needs. Secondly, a way forward

can be found by looking at major moral *principles* in health care, familiar as respecting autonomy, beneficence, justice and avoiding harm. If these are helpful, then they must be as applicable to this debate as any other. So we should be able to ask about how we should be respecting individual choices when people are dying, about what the greatest benefit for such patients might be, and who would decide that. We should want to consider all the possible harms which might face them, and how these could be minimized in a fair way, which was also consistent with other values and activities in that society.

This type of analysis would be possible both as *policy*, for people or groups of patients in general, but also could be, and ultimately should be, related to the *context* - about this person, in this situation, looked after by these people, in this way. The move from particular to universal, and back again, is hard and difficult work, but needs to be continually made, for practice is the laboratory in which we regularly test theory.

Examining clinical practice, reveals several interesting themes. One is that where euthanasia has become discussable and open, such as Holland, the enacted cases are nearly always part of a long term doctor-patient relationship, where trust and commitment have been established on all sides. Another is that there is always a balance to be struck between *saving life* and *reducing suffering*. Usually these aims coincide, but the difficult cases we need to examine are those where they do not, when longer life means only greater suffering. A third theme is the balance between the *biological* and *biographical*. The practice of medicine is classically seen as a art which uses science, and a biological science. But both the origins of illness or disease and the means at hand for an effective response often make us consider a very different model - a 'biopsychosocial' model, in which an individual's view of himself, his aims and story are all crucial to health and health outcomes. Elsewhere, we have published cases which show how the ways in which someone sees themselves not only influences the conduct of their life,

but also that of their dying. A dying cricketer refused to let a surgeon amputate his leg, because he saw himself as a sportsman and only suited to a mobile life. The request to Nigel Cox came from a farmer's wife whose life was spent in making sure her animals never got into the condition she found herself in. In some sense, these people saw that their dying should be related to their life; that the best death would be to die in a way which makes sense of the life, or at least, did not lose faith with it. It suggests that in the partnership between clinician and patient, the locus of decision making should increasingly be handed back to the patient as death nears, rather than the death become more and more a medical event. There are many duties laid on doctors; but this 'standing by but standing back', 'enabling and ennobling care' may be the hardest to achieve.

So what then does life mean to this individual and for the society in which she lives? Life's 'specialness' or 'uniqueness' is the reason for our absolutely correct revulsion against the taking of it in any way at all. Life is the basic gift without which all others lose their meaning. For some it is to be seen as *sacred*, offered by God. For some it is a *natural thing*, for some biological. For others its key is its humanness, that it expresses what is best about, and for, human kind. Sir Paul Reeves put his finger very near this, when he said earlier this year that 'life seems to be about giving permission to people to be what they've got to be'. (Address (on a Marae) at the NZMA Conference).

Is this a particularly slippery part of a slippery slope? At present, the law appears to define a proper human being as someone specifically *not* in control of the mode of her dying. What would happen if this were to change? We have seen the rejection of any involuntary act, but one such linked concern makes us realise how easy it would be for people to be pressurised subtly, but definitely, into taking a different view of themselves. The anniversaries of the last World War have been celebrated by genocide in Bosnia and nuclear explosions in the Pacific, and these serve to remind us

that human beings have not fundamentally changed in the last fifty years. We fear the removal of any bastion which might make life cheaper, or less different. Current Western politics have been moving away from a view of its citizens as all of equal value, and equally deserving of respect, to a more merit-based approach. Much as we probably deplore this, it is, perhaps, as well that we are having this debate now, where we can look at this change of approach realistically. I believe it is possible to

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provide safeguards to ensure that voluntary euthanasia really is voluntary. But there is clearly risk.

How do things work at present without resort to voluntary euthanasia? It would not be right for me, as a physician, to be the judge, but current practice does need to be reviewed. To take the example of terminal pain, acceptable and recommended practice would be to increase pain control, through the use of substances such as morphine, to the point where pain (or other similar symptoms) is properly controlled. The doses may then be such that there is a real and increasing risk of shortening life, through the drug suppressing respiration or by other mechanisms. This risk is justified, and held to be justified, by a version of the doctrine of *double effect*, developed by thinkers such as Aquinas. Many of the features and complexities of the original doctrine are disputed, and are beyond discussion in this article, but the core idea suggests the possibility of risking evil in pursuit of good; with a dying patient, the doctor being sure of alleviating suffering, thereby risking hastening death. To take this further would be to go deeply into a debate of *intentions*, and this is the problem which remains for the physician whose straightforward intentions are the other way round - a speedy dying and thus a reduction of suffering. (It was on this basis that Dr Cox was convicted.) Nevertheless, it would be important for the lay public to know

that accepted medicine as practiced in the United Kingdom (and, I believe, New Zealand) would not allow the patient to suffer in terminal illness, even if the dose of morphine required to achieve control of suffering would make death probable, rather than just a possibility.

Is this situation satisfactory? Certainly both experience and such studies as have been done, show that, in terms of symptom control, for most patients, it appears to be so. There remain, however, some important concerns. It is hard for a doctor at present to be open about what she is actually doing. There will be a few cases where symptom control is not satisfactory.

There are situations, for instance in some terminal neurological disease, where the symptoms would not naturally be seen as requiring morphine. The decision making lies mostly with the doctor. And there remains with me, I have to say, a fear that some foolish pharmaceutical company will find a method of severe pain relief which lacks the beneficial 'side' effects of morphine.

Thus I believe the current debate is timely. As a personal coda, I want, as a health professional, to be able to be appropriately open with my patients and with the world in general about what I could offer and what I am able to do, and why. That this is not completely possible at present, is due, at least in part, to the way in which some coroners and some courts are viewing this vital piece of medical work. Clinicians risk serious prosecution in some interpretations of the law. It is quite obvious to everyone else that current practice has the best of motives. Thus either current practice has to be accommodated through case law, or new law, with fully effective safeguards, must be enacted. Great courage is required for a patient who faces a difficult death. Courage is also needed for a professional to listen carefully, respond sensitively and to stay with her in all her suffering. It would be good if we could also see courageous decisions from coroners, courts and makers or enforcers of the law.