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Medical Law and Ethics

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I am most grateful for the care which volume editors have taken in carrying out the complex task of selecting and presenting essays which meet the exacting criteria set for the series.

TOM CAMPBELL
Series Editor
Centre for Applied Philosophy and Public Ethics
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Introduction

Over the last 20 or 30 years, the discipline of medical law has become an acknowledged area of specialism in most law schools and many medical faculties throughout the world. Although doubt has been expressed about whether or not it qualifies as a discipline separate from other legal areas, medical law has maintained an identity distinct from, albeit related to, more traditional legal disciplines.

In part, this is due to the challenges which dilemmas in health care present, and in large part it results from the almost unique closeness of medical law and ethics in general. The medical lawyer is required to engage with philosophy, medicine, law, nursing and social and political policy. New issues arise constantly, and often only the most sophisticated analysis will suffice to ensure that answers are provided, or at least routes through problems are identified. For this reason, medical law has become one of the most high profile and challenging of legal disciplines.

Apart from its profile, it is not unreasonable to suggest that medical law, and those engaged with it, are at the forefront of analysing and seeking to resolve intensely human, and often distressing, contemporary dilemmas. The developments in the 'new' genetics, for example (to be covered in a separate volume) have posed unforeseen and complex challenges to the way we live our lives, our self-perception and our interrelatedness with others. Long before genetics became a major issue, however, more traditional concerns dominated the field. Superimposed on them was medicine's other great 'revolution' – namely, the capacities of clinicians to circumvent infertility problems in those who would otherwise have had no opportunity to reproduce.

As medicine progresses, so the opportunity – and even need – to use human subjects in research expands. Although a practice with a long history, the treatment of human research subjects has long been controversial, and remains so today. Attempts to balance the interests of the individual with those of the community have sometimes resulted in concerns about the security of the individual research subject, and about the extent to which he or she is truly a volunteer in this process. Equally, the medical maverick finds a central place in this area.

Few subjects can be as emotive as the decisions made by individuals at the end of life. The recognition of the persistent vegetative state forced the law's involvement in matters traditionally thought of as private and required subtle, and controversial, reasoning in the search for a resolution. Equally, the general climate of respect for patients' rights has raised the question of the extent to which people should have rights in choosing their death, in the same way as they have acknowledged rights in choosing how to live.

Although many areas of medical law could have been chosen for this volume, I have confined myself to four broad areas – some new, some traditional. Even within the areas selected, of course, the range of issues which could have been considered is enormous, and selection was difficult. What I have tried to do in this volume is to select those essays which demonstrate most clearly both the legal complexities of the subjects and the human dilemmas contained within them. In a sense, it is invidious to choose some commentaries over others, some authors at the expense of others. What this volume does not claim is that the essays contained in it are undoubtedly the best; rather it asserts an admittedly personal, perhaps idiosyncratic, choice of both topics and commentators, in an effort to display the range and diversity of issues which make up modern medical law. As my intention is partly to demonstrate the nature of the analysis required of medical law, as well as exploring content, it is to be hoped that I will be forgiven for this.

The chapters in this book follow a straightforward plan. Parts I and II consider what might be called the more traditional issues in medical law – negligence, consent to treatment and reproduction. Parts III and IV address more 'modern' problems in medical law – human experimentation and research and issues at the end of life. Although primarily legal in content, the closeness of medical law and ethics is highlighted by the inclusion of some essays which are essentially pure philosophy, but which have direct relevance to the legal issues covered. Indeed, virtually all of the legal essays highlight the jurisprudential nature of the subject. These are not descriptive documents; rather they argue a case, using historical and contemporary explanations to critique and evaluate the law as it currently stands.

Negligence/Consent

In Chapter 1, Marjorie Schultz provides an excellent analysis of the move towards recognizing informed consent as a critical feature of patients' rights, and medical law in the USA. In her lengthy piece, she traces the development of the law in this area, in particular addressing the extent to which patient autonomy has become an interest seen as worthy of protection. Her conclusion, that a new model of authority in the doctor patient relationship is required, carries resonance even many years after this article was written. As she says:

> Medical decisionmaking involves the interwoven, overlapping and often competing claims of personal autonomy and professional competence. The challenge of regulating medical decisionmaking is to allocate the proper weight to each of these values. (p. 82)

Within the existing legal framework, Schultz claims that '[p]rotection of patient autonomy remains derivative rather than direct, episodic rather than systematic' (p. 83).

The creation of legal protection of patient autonomy is taken up by Gerald Robertson in Chapter 2. As informed consent is primarily a feature of US jurisprudence, Robertson explores the extent to which it has implications for UK law. Tracing the history of the development of informed consent in the USA, he re-emphasizes the extent to which it was a device used to enhance respect for patient autonomy. He also, however, concludes that additional, and policy-based, reasoning underlay its creation and absorption into common legal parlance in that country – namely, the desire to expand the liability of physicians. Although UK courts increasingly use the language of informed consent, Robertson points out that it forms no part of UK law. Indeed, that contention holds true even today, although some similarities to the US position may be observed in the approach taken by UK courts. However, Robertson's prediction that English (I would argue each of the UK's jurisdictions) law will probably seek to restrict the applicability of any such doctrine has been borne out in reality. Cases such as *Bolam* v. *Friern Hospital Management Committee*,[1] which have long been criticized for handing over to doctors the power effectively to set their own standards have been absorbed – albeit not in a wholesale manner – into leading cases such as *Sidaway* v. *Board of Governors of the Bethlem*

Royal Hospital and the Maudsley Hospital,[2] leaving the UK in a position whereby the amount of information legally required for a meaningful consent is heavily dependent on what other doctors would tell their patients. Robertson, therefore, was correct to predict that '... the doctrine of informed consent is unlikely to develop in this country and that consequently it will prove to be of limited scope in affording compensation to victims of medical accidents (p. 109).

The law's reluctance to elevate the standard of disclosure required, and thereby to give real meaning to patient autonomy, can partly be explained by the reasons which have traditionally been used to support non-disclosure. These were identified by Allen Buchanan, whose essay is reproduced as Chapter 4 of this volume. He identifies a number of lines of argument, which he subsumes under the general heading of 'Medical Paternalism', and argues that each of them can be defeated. In a powerful exposé of the inherent weakness of arguments for non-disclosure Buchanan indirectly challenges legal subservience to accepted medical practice, although he writes as a philosopher. It is, of course, plausible to argue that, since Buchanan wrote this essay, times have moved on, and certainly we have a generation of doctors and other health care workers growing around us for whom respect for patients is more than merely a mantra without meaning. Nonetheless, the attitude that, for example, patients will be harmed by disclosure about the truth of their condition, still lingers and carries weight. Even in those US states which follow the 'prudent patient' test, developed in the case of *Canterbury* v. *Spence*,[3] the notion of therapeutic privilege forms an integral part of the doctrine. Thus, although the *Canterbury* test seems to focus on the prudent or average patient, rather than on the prudent or average doctor, it remains permissible to withhold information likely to distress the patient. In this way, the withholding of truth, to which Buchanan so strongly objects, is built into even the more radical approach to disclosure of information.

This pattern is repeated on a worldwide basis. In Chapter 3, Danuta Mendelson takes us on a guided tour of the law of consent in much of the English-speaking world. As an Australian, she would doubtless see the case of *Rogers* v. *Whittaker*[4] as a significant development. This was Australia's first major strike against the dominance of the *Bolam* test, and may finally have sounded the death knell of the professional test in Australia. Mendelson's primary concern is to trace the development of the law in respect of consent to treatment and, more significantly, refusal of treatment in a number of countries. She concludes that the supremacy of autonomy in current common law is both unusual and to be regretted:

> Conceptually, the legal right to self-determination is, undoubtedly, a very significant and essential element of modern jurisprudence – people, in general, should be able to exercise control over their bodies in relation to undertaking or cessation of any invasive medical regimen. Nonetheless, there are a number of profound moral and human questions that sit uneasily with the declaratory statements of an ideologically pure notion of personal autonomy. (p. 180)

Whether or not one agrees with the ideology which underpins Mendelson's essay, it has increasing contemporary relevance, given the genetics revolution. The use of individual autonomy as a trumping value certainly has profound consequences when one person's exercise of autonomy may harm that of another person, as may well be the case in genetic conditions. The values of interconnectedness are, arguably, less demanding in the standard medical act, although Mendelson's concentration on the refusal of life-saving medical treatment does shed some light on her concerns about the use of a pure autonomy model, given that such decisions may also impact on others.

Reproduction

Part II of this volume begins with two very different essays on one of the most controversial issues in human reproductive choice – abortion. In Chapter 5 Ronald Dworkin analyses the conservative and liberal approaches to abortion. Of course, his analysis takes account of the fact that it is difficult simplistically to categorize people and their views in this way, but as a tool for analysis it serves the argument well. In his analysis, he focuses on two, potentially extreme, positions, with the Churches representing the 'conservative' perspective and 'feminism' the liberal. His central theme is encapsulated in the following quotation:

> . . . we cannot understand the moral argument now raging around the world – between individuals, within and between religious groups, as conducted by feminist groups, or in the politics of several nations – if we see it as centered on the issue of whether a fetus is a person. Almost everyone shares, explicitly or intuitively, the idea that human life has objective, intrinsic value that is quite independent of its personal value for anyone, and disagreement about the right interpretation of that shared idea is the actual nerve of the great debate about abortion. (p. 244)

In Chapter 6 Sheila McLean also surveys the pro- and anti-choice lobbies' positions on abortion, but from a different perspective. Here, the question is whether or not there is any ground on which agreement could be reached between these positions, and in particular she argues that there is an element of inconsistency in the anti-abortion lobby's arguments. With the exception of those who would always disapprove of abortion, the anti-abortion campaign hinges, she contends, on an inherently disingenuous claim for the moral high ground. Focusing on attempts by anti-choice protagonists to limit the legal availability of abortion to the earliest stages of pregnancy, McLean argues that this position is a complete contradiction of their professed concern with foetal life. Although not proposed as a practical solution, this essay argues that – for the sake of consistency – the anti-choice lobby should argue for minimum time limits rather than maximum ones. In this way, women could be relieved of their unwanted pregnancies and foetuses could also be salvaged.

In Chapter 7 David Meyers provides a clear and shocking account of the policy of non-consensual sterilization carried out in the USA in the twentieth century – a practice apparently endorsed by the public, and certainly by legislators. Most US states had laws in force which permitted, for example, the superintendents of institutions for the 'feeble-minded' to authorize sterilization without reference to the wishes of the individual (usually female). In some cases, women were only released back into the community after surgery to sterilize them, some only finding out many years later just what the operation had been for. Perhaps the most ringing endorsement of this policy can be found in the words of Oliver Wendell Holmes, remembered generally as one of America's most distinguished judges, when he said:

> We have seen more than once that the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the state for these lesser sacrifices, often not felt to be such by those concerned, in order to prevent our being swamped with incompetence. It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes . . . Three generations of imbeciles are enough.[5]

Meyers was one of the first writers to expose this situation, and he concludes:

> There must come a point to which medical advances have perhaps already brought us, where society – represented by a legislative majority – no longer has the right to use its knowledge to manipulate and mutilate the bodies of those it feels somehow do not fit the desired social mould. (Myers, 1971, p. 47)

In Chapter 8 Margaret Brazier addresses the other side of the reproduction coin – not its prevention but its facilitation. The UK is amongst those countries which have chosen to regulate assisted procreation by way of a dedicated statute. While other countries have a much more *laissez-faire* approach to assisted procreation, in 1990 the UK passed the Human Fertilisation and Embryology Act which can trace its genesis to the recommendations of the 1984 *Report of the Committee of Inquiry into Human Fertilisation and Embryology* (the Warnock Report). Although the Act is often held up as an example for other countries, Brazier concludes that:

> Because the British system is built on consensus, regulators, clinicians and scientists work well together. All those strengths benefit patients and promote British reproductive medicine as a success story. The price paid for consensus however is that all too often crucial issues of individual rights, the balance between individual rights and public policy, and issues of conflicting rights are skated over. (p. 298)

There is, she concludes, 'little conceptual depth underpinning British law' (p. 298). This view may well be thought to carry some weight, given the challenges which have arisen already to British law, for example the case of Diane Blood,[6] who sought authority to use semen removed from her dying husband and was effectively precluded from doing so in the UK because of the terms of the legislation (see, further, McLean, 1999). Equally, the cloning of 'Dolly' challenged what legislators had seen as an outright ban on cloning contained in the Act, as the technique used to create Dolly is not specifically covered by it. In light of this attempted ban, the recent parliamentary agreement to permit stem cell research, including cloning, seems to go against the spirit of the Act, yet the amendment will once again place British scientists in a position envied by many of their European colleagues whose countries prohibit research of this nature.

Yet, despite her critique of the law, Brazier also sees its benefits, and concludes that, both in the UK and elsewhere in Europe, countries have 'sought to fashion a scheme of regulation acceptable to its own culture and community . . .' (p. 324). Nonetheless, she suggests, those with the wealth and the technical know-how will be all too able to bypass the regulations in force by use, for example, of the Internet. Arguably this is an insurmountable problem, even were there to be a genuine drive for harmonization of laws. Already, people travel within Europe to obtain services – Mrs Blood was able to receive treatment at a clinic in Belgium, thanks to the Court of Appeal's insistence that she, like all citizens of the European Union, was entitled to move freely throughout Europe for services, including medical services. It seems unlikely that a global – even a European – consensus on the principles underpinning the availability of assisted reproductive techniques is attainable.

In Chapter 9 Susan Mattingly explores one possible model of pregnancy – namely, viewing the woman and the foetus as two distinct patient entities. Although the impetus for viewing pregnancy in this way might have been to generate foetal 'rights', Mattingly convincingly points out that this essentially backfires. If woman and foetus are viewed as separate patients, then there are potentially more obstacles to treating foetuses (since this involves invading the woman's body) rather than fewer. Duties are owed to both patients in this description of pregnancy, but '. . . the injunction against harming one patient involuntarily to help another is virtually absolute' (p. 328). In addition, of course, viewing the foetus and the pregnant woman as separate and distinct entities, generates the 'conflict' between them and poses problems which are difficult to resolve. As Draper has said:

> . . . in the maternal versus foetal conflict model, whoever wins, pregnant women lose. Resolving the conflict in favour of the mother gives her the liberty and the sole burden for deciding whether or not the foetus will live; she alone must sacrifice or live with the consequences. If the conflict model is resolved in favour of the foetus, women lose out again, since the sacrifice for saving life is extracted from them and them alone . . . (Draper, 1992, p. 1).

The implications of generating foetal 'rights' are further considered in Chapter 10 where Dawn Johnsen describes what she calls 'a dangerous conceptual move' (p. 335). Conceding that foetal rights had, at that time (1986), seldom been used to trump women's decisions, she nonetheless – and rightly – indicates the very real potential that such incidents may become more common. The range of ways in which women may harm embryos and foetuses by engaging in activities which are perfectly lawful is substantial, yet concentration on the foetus may lead to a situation where women's basic rights to live as they choose are damaged, if not rendered nugatory, at least for the duration of a pregnancy. Tracing the history of legislative and other activity with direct relevance to protecting the foetus, Johnsen argues that there is a resonance between the tradition of keeping women in the sphere of private (that is, family) life and out of the workplace, and the current trend in developing foetal rights.

Chapter 11 is a short, but immensely poignant, analysis by George Annas of one case in which the true consequences of prioritizing foetuses over women became distressingly clear. In his brief account of the tragic case of Angela Carder, Annas exposes the extent to which the law may collude with medicine to limit women's rights in the interests of salvaging their foetuses. In a hard-hitting critique of the judgment in this case (subsequently overturned after Angela Carder's death) Annas says that the judges:

> . . . treated a live woman as though she were already dead, forced her to undergo an abortion, and then justified their brutal and unprincipled opinion on the basis that she was almost dead and her fetus's interests in life outweighed any interest she might have in her own life or health. (p. 361)

Since Ms Carder's case, courts both in the USA and the UK have, on occasion, continued to place the interests of the foetus on a par with, or occasionally above, the rights which live and competent women are generally conceded to hold. From the advances in medical technology have come a plethora of ethical and legal dilemmas. If nothing else, this situation shows the extent to which progress is seldom value-neutral and has the potential to challenge the analytical skills, and sheer humanity, of the law.

In the final chapter of Part II, J.K. Mason moves us on to a different, but related, topic. Chapter 12 provides a thoughtful and intelligent analysis of *McFarlane* v. *Tayside Health Board*,[7] a Scottish case which was ultimately decided in the House of Lords. As the supreme civil court in the UK, the House of Lords in this judgment has effectively bucked the trend of permitting recovery of damages for the additional costs of bringing up a child born after the parents had attempted to ensure, in this case by contraceptive surgery, that they would have no further children. Mason expertly exposes the inconsistencies in approach by tracing the history of what are often called wrongful birth cases (although he believes that *McFarlane* is in fact a case of what he calls wrongful pregnancy) in the UK. However labelled, *McFarlane* has apparently reversed a trend, which was observable both in the UK and in other countries, of moving away from the 'child as a blessing' policy towards the recognition of the reality of the additional costs associated even with a wanted and much loved child. Arguably, the House of Lords, for reasons which do not stand up well to scrutiny, have simply replaced one policy-based approach with another, but not necessarily better, one. This essay invites us to examine what happens when policy is presented draped in the cloak of reason. As Mason concludes, 'it is difficult to see the House of Lords' judgements in *McFarlane* as other than a scholarly and thoughtful elaboration of a single word – distaste – and it could be argued that we are entitled to disclosure of better grounds on which to reverse an established line of decisions' (p. 377).

Human Experimentation and Research

Part III of this volume returns to consent issues, but now in the context of the use of human beings in research and experimentation. Arguably, the most important essay ever written on this subject makes up Chapter 13. Henry Beecher's shocking exposé of research practices in the USA heralded ever closer scrutiny of the aims and methods of human research. In this short, but passionate, essay Beecher generated serious doubts about the adequacy of international and national control over the use of human subjects in research. In this area above all it might have been anticipated that monitoring would be close and demanding. Following the Nazi atrocities of the Second World War, the Nuremberg Code, developed out of the war crimes trials, was expected to ensure that humans were never again subject to such cruelty. The first Principle of the Code demands that free and voluntary consent is given before research can be ethical or legal, yet Beecher concludes, somewhat unhappily, that some subjects of experiments '. . . would not have been available if they had been truly aware of the uses that would be made of them' (p. 381).

Beecher gives 22 examples of unethical research, although he was also able to claim that many more could be identified. This essay, first published in 1966, is, of course, somewhat elderly, and it might be thought that its age militates against its inclusion. However, to imagine that unethical research or experimentation does not continue to occur would be naïve, and Beecher's contribution reminds us how easy it may be, even in a sophisticated community, for dubious research to occur. This is so despite the increasing scrutiny of research protocols by ethics committees.

Alastair Campbell in Chapter 14 brings us more up-to-date with his brief analysis of the experiment conducted on women cancer patients in a New Zealand Hospital which came to light in 1987. Despite increased surveillance of the use of human subjects and the existence of an international code dedicated to human experimentation and research – the Declaration of Helsinki – one doctor was able to use women, without their knowledge and over a period of 15 to 20 years, to test his own hypothesis that cervical carcinoma *in situ* would virtually never progress to invasive cancer. Women were, therefore, not offered the standard available treatment. An Inquiry was set up, which discovered – amongst other things – that the fact of this experiment had been known to the hospital authorities, yet no one tried to stop it and no extra care was provided for the women concerned. Although condemning the experiment, Campbell nonetheless takes some comfort from the thoroughness of the Committee of Inquiry's work, and concludes that its report is '. . . a powerful endorsement of the centrality of ethical issues both in professional education and in the public debate about the quality of health care' (p. 396).

In Chapter 15 Ian Kennedy undertakes a thorough analysis of the law in this area, viewed from the UK perspective and incorporating European Directives. Although he does not attempt a full-blown critique of existing regulation of human subject research, the model which he demonstrates is potentially of value in the assessment of the pitfalls into which researchers may fall. In addition, the UK model can usefully be contrasted with regimes in force in other jurisdictions.

Death and Dying

The final section of the book concerns issues at the end of life. Many of the essays here are relatively brief, but they are designed to provide the reader with a taste of the range and complexity of issues which arise when decisions are made at the end of life.

In Chapter 16 Helga Kuhse discusses a contentious aspect of end-of-life decisions – the living will debate, holding, against Robertson's argument in Chapter 17, that the fact that people can in fact be apparently happy in, for example, a demented condition does not mean that this should take precedence over previously expressed wishes. She also explores the notion of psychological continuity, and notes that '[g]iven that the continuity between mental states admits of degrees, the issue of when one person has been replaced by another remains somewhat vague' (p. 441). Indeed, she notes the argument that:

> As long as strong psychological connections continue to exist, there is little reason to doubt that the executor of the advance directive and the patient are the same person. Similarly, there is little reason to doubt that a patient who has slipped into a persistent vegetative state and has irreversibly lost the capacity to experience states of consciousness is not the same person as the executor of the advance directive. The reason is not that the patient is a *different* person, but rather that with the permanent loss of the ability to experience *any* psychological states, the patient is . . . no longer a person. (p. 441)

Persons, for Kuhse, are 'conscious beings, who have the capacity for rationality, self-consciousness, and purposive agency; they have the ability to see themselves as existing over time, that is, they are not only living in the present, but have the mental capacity to span time' (p. 442).

Kuhse's refutation of Robertson's approach, therefore, hinges critically on the distinction between persons and non-persons. As she says:

> . . . those who argue that advance directives rest on a confused understanding of personal identity may well be correct, but acceptance of that position does not by itself provide sound reasons for overriding refusals of life-sustaining treatment. Rather, an examination of plausible understandings of the concepts of 'person,' 'human individual,' and 'interests' may well lead one to conclude that the implementation of advance directives will, other things being equal, be justified, even when the now incompetent patient is not experiencing suffering and distress, and seemingly is capable of experiencing some simple but psychologically disjointed pleasures. (p. 447)

In Chapter 17, we move to John Robertson's essay, critiqued by Kuhse in the previous chapter. In this essay Robertson has 'second thoughts' about living wills and, in a brief, but influential, analysis of the rationale for living wills, he seeks to expose their inherent confusion. In seeking to control life (or more accurately, death) after loss of competence, the presumption of proponents of the living will is that it permits individuals to retain control over the manner of their dying when they are no longer able to express their values or decisions. Robertson, however, makes one very telling point. As he says:

> The problem, however, is that the patient's interests when incompetent – viewed from her current perspective – are no longer informed by the interests and values she had when competent. The values and interests of the competent person no longer are relevant to someone who has lost the rational structure on which those values and interests rested. Unless we are to view competently held values and interests as extending to situations in which, because of incompetency, they can no longer have meaning, it matters not that as a competent person the individual would not wish to be maintained in a debilitated or disabled state. (p. 452)

Thus, Robertson concedes the values apparently embodied in respecting the living will, but would suggest that there is an inherent fallacy or confusion surrounding their enforcement. A classic example of this tension might well be the competent person who, having witnessed what has happened to an elderly relative, makes out a living will indicating that, should they become demented, they would not wish to have any life-sustaining treatment, even antibiotics, made available. That same person, however, once demented, might in fact be, for all intents and purposes, perfectly happy. This is a powerful image, and one which doubtless has influenced the views of organizations such as the British Medical Association which counsels that advance statements should be followed only when they are well-informed and specific as to the conditions included and the treatments which are unacceptable.

The value of advance directives is also taken up by Joanne Lynn and Joan Teno in Chapter 18. Writing in the aftermath of the passing of the Patient Self-Determination Act (PSDA), in the USA, they avoid the theoretical for the practical. In their view, '[f]ormal advance directives are not worth much unless they can be shown to improve decisionmaking' (p. 457). Their plea, therefore, is for sound empirical research into the actual, as opposed to the theoretical, impact of the PSDA which was 'intended to encourage patients to claim their rights in regard to decisionmaking' (p. 455). In sum, they argue that 'advance directives have been proposed as the answer to the problem of how to empower patients so that they maintain control of their care even when incompetent. We have not yet shown that directives will answer that need' (p. 458).

Chapter 19 comes from two commentators who have written extensively on proxy decision-making, and whose voices in this field are highly influential. Staying with the subject of advance directives, Linda and Ezekiel Emanuel take the debate one important step forward, recognizing the doubts that have been expressed about the extent to which advance directives actually can, or do, enhance patient choice. The limitations on advance directives can be categorized as personal – the inability of the individual to understand all relevant issues, and their potential to change their mind – and procedural. The latter relates to the fact that in few countries, with the possible exception of Denmark, do people actually make an advance declaration in any event. Evidence abounds that people may not understand medical information, and decisions made on flawed understanding may not, therefore, actually serve the purpose claimed for advance directives. Equally, the option of appointing proxy decision-makers to carry out the wishes of the now incompetent person has been shown to be flawed. Not only do the Emanuels find evidence that people do not talk things through thoroughly with a designated proxy (assuming that they appoint one) but that '[t]he patient's prior wishes and proxy predictions of the patient's prior wishes in circumstances other than the patient's current health overlap only from 33 to 68 percent of the time' (p. 462).

However, there are also others for whom end-of-life decisions must be taken, and where no prior wishes are recorded. In an effort to ensure that these patients may also benefit from the control that the advance directive seems to permit, they propose that 'default guidelines based on a "local patient community medical directive"' should be considered for 'incompetent patients with no advance directives' (pp. 463–64). These, they suggest, could be drawn up by surveying a randomly selected group of other patients in the health care facility, using robust survey methodology. Second, guidelines could then be developed by an institutional committee with broad representation from both medicine and beyond. Third, the preliminary conclusions of these committees should be put to the test by involving the wider public, and the guidelines should be widely publicized. As to implementation, they conclude that:

> When an incompetent patient lacks an advance directive, the health care team would interpret the default directive to apply to the patient's situation in the same way that it currently interprets personal instructional directives. (p. 465)

Although they concede that the use of the default directive would be likely to be infrequent, their proposals are designed to 'help realize the ideal of patient autonomy in life-sustaining treatment decisions for the underrepresented group of patients who have no advance directive' (p. 468).

These proposals are manifestly contentious because, for some, they may simply represent a move towards formalizing, under the cloak of respectability and democracy, the premature ending of some lives. From the other perspective, of course, they represent a genuine attempt to balance the rights of those who have made prior choices with those who have not. In light of people's continued apparent apathy about making such choices, and the increasing numbers of people who will die after a period of incompetence, the Emanuels have at least provided a further twist to the debate about advance directives.

Finally, in Chapter 20, Ann Sommerville gives a clear and thoughtful account of the approach to advance directives in the UK, and explores the approach of the British Medical Association. In concluding that 'advance directives – at least in their present form – may not be the best or only answer for people with deteriorating mental facilities . . .' (p. 488), she nonetheless argues that their real value may in fact lie in the opportunity they can, or should, provide for dialogue between doctor and patient.

In Chapter 21, John Keown provides a compelling critique of the Dutch approach to euthanasia and assisted suicide. Until last year, these remained outlawed in the Netherlands, although tolerated providing that certain criteria are met. A well-known opponent of legalizing euthanasia, John Keown highlights what he sees as the reality of the Dutch situation by analysing the available figures in such a way as to demonstrate that the actual incidence of euthanasia in the Netherlands is considerably higher than officialdom will admit. Although the Dutch experience is often held up as an example which the rest of the world could follow, it is not without its critics, even on grounds different from those Keown identifies. For example, the regulations which currently govern euthanasia require that doctors report cases before they know whether or not they will be prosecuted (arguably, likely to lead to significant underreporting), and the system is essentially based on medical paternalism rather than on the rights of patients to act autonomously in choosing when to die. Keown's opposition is more fundamental than that, and there is no doubt that his analysis of the rate of doctor-assisted dying in the Netherlands is disturbing. If his analysis can be criticized, however, this would be on the basis that no comparison is made with the rates of doctor-assisted deaths in jurisdictions which continue to outlaw both euthanasia and assisted suicide. Doubtless, these figures are unlikely to be readily available, but it does mean that Keown is unable to compare like with like.

In Chapter 22 John Griffiths discusses one of the more controversial cases in the history of euthanasia in the Netherlands – the *Chabot* case. Arguably, it is decisions such as this which add fuel to the concerns expressed by Keown and other commentators. Although public acceptance of euthanasia in the Netherlands seems to exist, before this case the general presumption had been that it would be available primarily to those suffering from physical problems, and certainly not to those whose mental condition was in doubt (not least because of the requirement for a free and voluntary consent). The facts of this case, however, moved the debate forward and expanded the groups who might be able to take advantage of the Dutch approach. Here, a doctor assisted a woman suffering from an 'adjustment disorder consisting of a depressed mood, without psychotic signs, in the context of a complicated bereavement process' (p. 530) to die (without, interestingly, arranging for her to be examined by other colleagues, although he had sought their advice). In carrying out this action Dr Chabot technically could be said to have operated beyond the strict confines of the regulations laid down, but the Court of Appeals accepted that assistance with dying could be extended to those who were not suffering from a somatic or terminal condition.

This ground-breaking decision has been the subject of much ethical and legal debate, as – for some commentators at least – it shows that the slippery slope argument does work: tolerance of assisted dying in extreme cases becomes tolerance in less extreme circumstances, or in cases where there may be concerns about the requesting individual's capacity. Griffiths concedes that there is evidence of 'medical practices which shorten life, in the cases of non-competent or of competent but not-consulted patients' (p. 542) and agrees that the data are 'a matter of concern' (p. 542). Nonetheless, as he points out:

> There is really not a shred of evidence that the frequency of this sort of behaviour is higher in the Netherlands than, for example, in the United States; the only thing that is clear is that more is known about it in the Netherlands. In short, there is no reason to assume . . . a causal relationship between limited legalisation of euthanasia and 'lack of control' over other sorts of medical behaviour. (p. 542)

Griffiths also notes that Dutch euthanasia law, with the *Chabot* case, seems 'to have taken a decisive step away from the doctor-centred approach which has dominated legal development up to now . . . toward patient self-determination' (p. 541). The consequences of this, of course, might be that the qualifying characteristics which must presently be satisfied could be limited or removed altogether, making a request for assisted death from anyone, irrespective of their medical condition, acceptable. This would, of course, not be uncontroversial. Many of those who have, however reluctantly, reduced or lost their opposition to assisted death, have done so on the basis that for some people, in the final stages of a terminal illness, the suffering involved