Disclosing a Value System in a Living Will Could be in Your Best Interests

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By

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THIS BOOK IS DEDICATED TO MY MOTHER AND LATE FATHER
WITH MUCH LOVE

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SUMMARY

Whilst doctors are recognised for being expert in medical matters they are nevertheless generally required by law to obtain the consent of a competent adult patient prior to administering a medical treatment.[1] The need for consent underpins the right of a competent adult patient to refuse treatment, even life preserving treatment. Accordingly, bodily inviolability is a fundamental principle of law and violation of it, even for benevolent reasons, is prima facie punishable. Instead of which a competent patient has a right to self-determine what shall happen to their own body. In this way the subjective decision-making standards and methods of a competent patient inform, and are made determinative, of any decision to accept or reject a medical treatment.

It is against this general background that the comments of Lord Goff in the case of *Bland* should be considered. There he suggested that the best interests test should comprise of something more than purely professional appraisal of a person's medical welfare.[2] To confine the test in this way, he said, would be inconsistent with the primacy given to the principle of self-determination and would '*downgrade the status of the incompetent person by placing a lesser value on [their] intrinsic worth and vitality*'.[3]

So as the title to this study suggests I am primarily concerned with legal provisions governing medical treatment decision-making processes in respect of formerly competent adult patients. More specifically it questions whether the values, beliefs and preferences of members of this

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[1] The term generally has been used to denote the fact that the inviolability of persons is a fundamental principle of law and in a medical context this means that the administration of a medical treatment is dependent on some form of legal authority. As the primacy of the moral principle of autonomy is established in law doctors must obtain legal consent prior to administering a medical treatment. However, there are circumstances where the law remains paternalistic and medical treatment can be administered on the basis of an alternative legal authority, for example, the Mental Health Act 2007.

[2] Airedale NHS Trust v Bland [1993] 1 All ER 821 HL

[3] Airedale NHS Trust v Bland [1993] 1 All ER 821 HL

patient group should be more favourably promoted, i.e. used and made determinative, in medical treatment decision-making processes concerning them based on contemporary understanding and application of the moral principle of autonomy. Naturally this depends on whether a person's value system can be accurately ascertained, recorded and protected to ensure that it is most fully promoted and respected in the future should a loss of decision-making capacity leave them unable to determine matters contemporaneously.

Accordingly, the premise underlying this study is that the autonomous values, beliefs and preferences of a formerly competent person should be ascertained and recorded so that they can be understood and used by others to determine whether, and if so what, medical treatment is in the actual best interests of the patient. Essentially bodily integrity would be safeguarded if a surrogate decision-maker was able to determine what the patient would decide if they were competent to make that choice. A situation that is most desirable if we are not to downgrade the moral status of this particular group of incompetent patients.

INTRODUCTION

This study seeks to answer the question of whether the values or value system of a competent person, that have been disclosed in a living will, could play a role in medical treatment decision-making processes concerning them under the Mental Capacity Act 2005.[1]

Aims of the Investigation[2]

- To explore the goals of medicine as well as the key ethical principles of the medical profession to draw attention to the obligations that are significant to treatment decision-making processes
- To examine the moral principle of autonomy to establish the context in which a person is respected as an autonomous moral agent with the right to self-determination and to its significance in relation to the question of what a good life is or should entail
- To investigate the general legal framework for the provision of a medical treatment in respect of a capable patient to determine whether autonomy is the primary principle of medical law and if it is to consider whether patient values are also respected in law
- To inquire into the law in respect of the incapable patient to see what approach is taken to safeguarding the autonomy and welfare interests of formerly competent patients
- To research the nature and scope of an advance decision to refuse a medical treatment since these are an exception to the principle that a doctor must act in the best interests of a mentally incapacitated patient
- To analyse the concept of values and of a value system to see how these can be articulated so as to inform the assessment of

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[1] In this regard I wish to thank Professor Michael Gunn, who acted as director of studies during the first year of my study, for inspiring me to undertake this project.

[2] In this regard I wish to thank Ms Kay Wheat for assisting me to develop a structure that helped me to focus more precisely on the theme of this work.

best interests and how they might be incorporated into advance decisions

- To inquire into the usefulness and effectiveness of the Mental Capacity Act 2005 in promoting autonomy when someone has disclosed a value system in a living will with a view to suggesting ways in which the law might be made to work better if the MCA is found wanting in this regard

Research Context

My research question seeks to address a social issue that directly or indirectly affects many members of society. It arises out of the fact that persons wish to survive and to lead a good or flourishing life and trust that medical science will, when necessary and appropriate, help them in that endeavour. We are fortunate to live in an era where death results far less frequently from serious injury or illness due to advances in medical science and this is obviously beneficial for those whose health is subsequently fully restored. However, contemporary medicine cannot always be relied upon to produce such a positive outcome and in cases where mental health has been unduly compromised doctors may continue to care for a patient in their best interests. Another consequence of our era is that people are living for longer. This has precipitated a proportionate rise in the incidence of diseases such as dementia and once a victim's decision-making capacity has been irretrievably compromised by mental deterioration, their future health and welfare needs will also be determined by reference to the best interests test. Accordingly, an increasing number of people are, or at risk of being, prevented from exercising their right to self-determine what shall happen to them in a medical context.

The irony is that this is taking place at a time when the primacy of autonomy and the right to self-determination have become more firmly established in medical law.[3] Certain significant influences contribute to this being so. Our law is intimately concerned with human welfare and morality and as statutory and common law provisions tend to support the view that we are all equal before the law it is important that the law should not be structured in such a way as to deny moral equality. Unfortunately,

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[3] See, for example, *Chester v Afshar 2004 WL 2289136*

there is no definitive way to settle questions about human welfare.[4] Each person is a unique individual and as society is inherently pluralistic no consensus of opinion has formed around which goods and social practices we should adopt and why. If the law is to remain neutral in the face of competing and conflicting ideas about what a good life for humans should entail then one of its primary functions in regulating human conduct should be to recognise and protect certain basic liberties and freedoms of all persons.[5]

In this regard the fundamental principle of bodily inviolability is adopted in law to reflect the special significance[6] and importance members of society attribute to the human body and life.[7] Primacy is however accorded to the principle of autonomy.[8] Philosophical reflections as to the value of autonomy relate particular facts about humans and their nature to the view that human life has special significance. The dominant view is that humans have an intellect that gives them the capacity to think, to reason and to be rational and because they can be trusted to make decisions and act on their own behalf in accordance with a reasoned set of principles or laws they should have freedom to pursue a life of their own choosing.[9] Nevertheless, they like other creatures also receive information from their senses. Human beings are therefore confronted by a mixture of rational and non-rational impulses. However, the will, which is essentially autonomous, links these two aspects of them and it can be mobilised to

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[4] For example, Mill and Bentham both considered that the principle of utility was the primary principle of morality but differed in their views about how the principle should be used to maximise human happiness

[5] Dworkin Ronald, Justice in Robes, 2006, The Belknap Press of Harvard University Press, Rawls and the Law, p.253

[6] There is general agreement that human life can be distinguished from all other life forms on the basis of the intellect. It therefore follows that this is the source of many of the concepts and ideas we use to uphold the notion that human life has special significance and importance, for example, dignity and morality and as each human life deserves to be respected as something special each of us should always be treated as an end and should never be treated merely as the means to the end of any other.

[7] *Re F (Mental Patient: Sterilisation) [1990] 2 AC 1 HL*

[8] *Re F (Mental Patient: Sterilisation) [1990] 2 AC 1 HL*

[9] See Immanuel Kant

override their more basic instincts.[10] Persons should therefore be treated as autonomous creatures of moral worth and dignity.

Therefore, the principle of autonomy is an important principle of law because it establishes the idea that person's value being in control of their own person and life.[11] A good life is in other words one where persons have freedom to pursue whatever is of value to them, i.e. a good life is one that is self-constructed. Accordingly, philosophical reflections on the value of autonomy support the view that mankind is better off when individuals are respected as sovereign masters[12] who willingly accept personal responsibility for their decisions and actions.[13]

Consequently, one of the ways that we show our respect for persons, in relation to medical treatment decision-making processes, is to allow them to self-determine, in accordance with their own values, beliefs and preferences, the matter of whether to accept or reject an offer of medical treatment, including cases where treatment may preserve life. In this way respect for autonomy is allowed to triumph over the sanctity principle; the desire to survive is a potent force within most rational persons but when good physical and/or mental health has been irretrievably compromised, it may not, on every occasion, be entirely irrational for some people to view an earlier death as being preferable to a continued life of intolerable mental or physical pain, indignity and restricted freedom.[14]

This is reflected in law as the general rule is that a doctor who administers a medical treatment without obtaining their patient's consent commits a battery.[15] This fact should be weighed against another. The underlying objective of medicine is to benefit the patient and physicians are people who possess skills and expertise in the practice of medicine. Moreover,

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[10] When the will operates freely and independently persons are more inclined to act rationally on the basis of reasoned deliberation rather than on the basis of sense perception alone

[11] Bodily security is an essential pre-requisite to individual exercises of self-determination

[12] According to Kant persons should always be treated as an end and never solely as the means to the end of any other

[13] Most moral and legal philosophers support, or at least do not detract from this view, see Kant, Mill, Bentham, Dworkin and Raz

[14] *Airedale NHS Trust v Bland [1993] 1 All ER 821 HL; Re B (Consent to Treatment: Capacity) [2002] EWHC 429 (Fam)*

[15] *Re F (Mental Patient: Sterilisation) [1990] 2 AC 1 HL*

medical professionals are ethically and legally regulated to act in the best interests of their patients. They are in other words bound to practice medicine beneficently and yet in law this is an insufficient justification for divesting persons of their basic liberties and freedoms or right to autonomy. Consequently, the law preserves the right of a doctor to determine, as medical expert, the form of treatment the patient should receive in their medical best interests but it is quite clear that beneficence should not be allowed to override autonomy when it comes to accepting or rejecting an offer of medical treatment. This is to reflect the fact that persons confer value on a wide variety of goods and as such it is impossible to define well-being solely in terms related to medical well-being. And when welfare is considered more broadly doctors are in no better position than anyone else to know whether what is in someone's medical best interests will also be in their actual best interests all things considered.

To that end consent must be legally valid if it is to provide physicians with a defence to the crime or tort of battery. As autonomy is the primary value governing treatment decision-making processes doctors are required to ensure that patients have the requisite level of capacity to make the decision they purport to make and in this regard all adults are presumed competent to make decisions and act on their own behalf.[16] In cases of doubt a doctor will seek to determine whether someone is suffering from an impairment or disturbance of the mind or brain[17] that would prevent them from understanding[18] and retaining[19] relevant information so that it can be used[20] to make a decision which they can communicate.[21] The decision of the patient must also be the decision of the patient and here it is important that the patient reached their decision about what to do voluntarily in that it was their own will that had been expressed on the matter and not that of some other interested party.[22] Finally, all medical treatments carry with them potential benefits and harms that may or may not materialise in a particular instance. Consequently, in order for consent to be legally valid it should be informed also so that the purpose of the

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[16] Mental Capacity Act 2005, s.1(2)
[17] Mental Capacity Act 2005, s.2(1)
[18] Mental Capacity Act 2005, s.3(1)(a)
[19] Mental Capacity Act 2005, s.3(1)(b)
[20] Mental Capacity Act 2005, s.3(1)(c)
[21] Mental Capacity Act 2005, s.3(1)(d)
[22] *Re T (Adult: Refusal of Treatment) [1992] 4 All ER 649 CA*

law, the inviolability of persons, is not frustrated but fulfilled.[23] In order to escape liability for the intentional tort of battery[24] doctors are required to inform their patients of the nature and purpose of medical treatment(s) and to inform them of the consequences of exercising their right of choice one way rather than another.[25] Doctors are also required to inform their patients of the risks inherent in treatment and to answer any questions they may field honestly and candidly.[26] Thus part of the reason why the patient's right to self-determination is legally protected is to enable them to arrive at a treatment decision having considered which harms they would wish to avoid and which risks they may be willing to assume in order to restore their personal sense of well-being. The question of whether the patient received sufficient information for their needs, i.e. to protect their own welfare and other interests, including that pertaining to risks which may or may not materialise, is thought to be a matter that should properly be considered in accordance with the standards proposed by the unintentional tort of negligence.[27] This is despite the fact that the way in which someone exercises judgment may be heavily influenced by information pertaining to the nature and severity of harms that may ensue from their decision when these entail a possible threat to their basic liberties and freedom of action in the future.

Self-evidently, the law's requirement for consent chiefly resides in the right of a competent patient to be maintained inviolate and free from bodily harm. Accordingly, the right to refuse necessary and appropriate medical treatment, even life-preserving treatment, is an essential element of autonomy. Moreover, the law determines that personal welfare and interests are best safeguarded by the subjective decision-making standards and methods of patients and therefore not only are their values, beliefs and preferences of paramount importance to decision-making processes concerning them but so too is their subjective evaluation of the benefits and burdens of the medical treatment they have been offered. Autonomy is then an important concept in the context of medical treatment decision-making because it allows patients to protect their own body[28] and welfare interests. It also serves to counter medical paternalism.

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[23] *Chester v Afshar 2004 WL 2289136*

[24] The standard of disclosure to escape liability for battery is restrictive in the sense that information about risks, which may or may not arise, do not have to be given

[25] *Chatterton v Gerson [1981] QB 432*

[26] *Chester v Afshar 2004 WL 2289136*

[27] Ibid

[28] Through the act of giving or withholding their consent

However, because the right to bodily inviolability is obtained through the right to self-determination it is open to question whether the right to autonomy is necessarily contemporary. The principle of inviolability is non-discriminatory and therefore every person has a right to be maintained inviolate and free from harm which means that every person should have the right to self-determine what happens to their body. However, the patient's right to self-determination flows from legal capacity. An issue in relation to mentally incapacitated patients is whether they too enjoy a similar right to medical treatment or to the withholding or withdrawal of necessary and appropriate medical treatment as do competent patients to consent to, or to refuse to consent to, medical treatment.

In *Re F*, for instance, Lord Bridge thought it axiomatic that in cases of medical necessity treatment which is necessary and appropriate to preserve the life, health or well-being of an incompetent patient may lawfully be administered without their consent provided that a doctor has acted in the patient's best interests.[29] The incompetency of the patient should not in other words be used as an excuse to deny vulnerable persons their basic right to medical care and treatment. Whilst, in the case of *Bland*, Lord Goff suggested that to subject an incompetent patient to a medical treatment based purely on professional opinion of what was in their medical best interests would not only be inconsistent with the importance we attach to autonomy and to the right of self-determination but it would also downgrade the status of the incompetent person by placing a lesser value on their intrinsic worth and vitality.[30]

What should happen then when a person suffers a loss of decision-making capacity? Is the patient's right to autonomy greater in these circumstances than their right to beneficence or to the state's interest in the preservation and sanctity of human life?[31] Should a person in a persistent vegetative state who will never regain cognition and whose vital processes are being maintained by a mechanical respirator and nasogastric tube be required to accept bodily invasions of this nature and frequency?[32] Or is the right to bodily integrity so fundamental that the right to autonomy should not be disregarded solely on the basis that their condition prevents them from

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[29] *Re F (Mental Patient: Sterilisation) [1990] 2 AC 1 HL, p.52*

[30] *Airedale NHS Trust v Bland [1993] 1 All ER 821 HL*

[31] Mental Capacity Act 2005; *Airedale NHS Trust v Bland [1993] 1 All ER 821 HL; In the matter of Karen Quinlan, 70 N.J. 10 Supreme Court*

[32] Ibid

exercising their right of choice?[33] If so, how is moral equality to be achieved? Upon what principle can autonomy best be protected, advanced and vindicated?

Conversely, what scope should be given to autonomy within the context of treatment decision-making on behalf of incompetent patients? Is there a danger, in a political democracy, that in respecting autonomy certain other important principles might fall into decline through misuse or become redundant through unthinking adherence to particular ideas about goods and social practices? For example, should a competent person be able to decide what happens to their incompetent self at some future point in time? Also, given the importance we attach to the sanctity principle and to the preservation of life how should the withdrawal of life-sustaining procedures, which will hasten the death of the patient, be regarded?[34] Finally, if we are not to abandon people to their autonomy isn't there a need for society not only to be just but to show that it is just also?

These various thoughts and comments stimulated my interest in the situation of formerly competent patients. More specifically I wished to examine legal provisions governing the doctor-patient relationship in respect of this patient group to determine whether their rights are coterminous with those of a competent patient and if not whether there was scope to improve upon current law.

Research Design and Methodology

This study is ultimately concerned with protecting and promoting the autonomy of formerly competent patients. As I wished to make suggestions for how the law might be made to work better in this regard it was possible for me to conduct a comparative study by seeking counsel from legal systems in alternative jurisdictions. The USA being foremost amongst them based on its long standing history of recognising and protecting the basic rights and freedoms of citizens constitutionally. There the Patient Self-Determination Act 1990, which is a federal law, seeks to promote patient autonomy but also to reduce costs associated with unwanted medical care. This statute requires hospital staff to inform patients of treatment options including the right to refuse treatment and by extension of right to die information and their advance directive options.

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[33] Ibid
[34] Ibid

Allied to which most States implement legislative provisions of their own - Natural Death Acts.[35] For example, Idaho and California have both implemented legislation that sets out the procedures to be followed for limitation of treatment, including life-sustaining treatment when a patient is terminally ill or suffers from an irreversible condition. Issues surround the definition given to 'terminally ill' etc. They also establish documentation to cover specific health situations. These can be equated to a traditional advance decision except that completion of one of these establishes clear and convincing evidence of the patient's wishes, i.e. the advance directive is valid and applicable. Beyond that these statutes generally seem to encourage the appointment of a surrogate decision-maker, who must not be the patient's doctor, to make decisions on their behalf in good faith and in accordance with their former wishes under the principle of substituted judgment. Use of the best interests principle is reserved for those cases where the wishes of the patient are unknown. Of course an issue with this is that an increasing number of people will not have anyone that they can or may wish to appoint into that role. In those cases it is at least arguable that the law has been structured in such a way as to deny moral equality.

I was, however, more interested in conducting a theoretical study because I wished to examine the philosophical foundations of medical law to see how this particular area of law was derived as a prelude to examining the relationship between moral philosophy and law in relation to competent patients. The next question that had to be addressed was whether, and if so how, considerations that should apply to a competent patient are applied in a situation where a patient has suffered a loss of decision-making capacity. Essentially, I examine the legal frameworks that apply to medical treatment decision-making processes in respect of competent and incompetent patients to see how the law works in practice so that I could form a view that was both valid and reliable about why it might fail to deliver what it promises in a particular instance or might not work as well as intended.

As with all things ethical questions concerning the application of moral standards and ideas about what is right and wrong human conduct become refined and modified over time to take account of contemporary conditions

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[35] Parallels can be drawn with Europe, I think, where the European Parliament issue Directives which require member states to achieve a particular legislative result without stipulating the means for doing so. Essentially state legislators have discretion to decide how to implement Directives.

possibly not envisaged by the likes of Kant and Mill. The contribution of medical science and technology for example to human welfare is outstanding but we must also learn how best to live with the consequences of its successes and limitations when these give rise to new moral dilemmas that are a source of considerable debate amongst members of society. In this regard contemporary moral and legal philosophers build on the work of their predecessors, whilst retaining its basic structure, to shine a light on the various factors that should be considered by those who attempt to find solutions to current ethical issues and I wished to draw on a valid and reliable body of knowledge that offered relevant, related and contrasting ideas about the value of autonomy so that I could make suggestions for how the law might be made to work better.

Since persons are moral subjects[36] a close connection exists between moral and legal systems, both are essentially concerned with human welfare and therefore with right and wrong human conduct. It was therefore possible for me to engage in classic legal scholarship which typically involves the synthesis, evaluation and critical analysis of key publications that are relevant to my area of study. The fact that data has been collected from some of the most distinguished academics in the field should ensure that my findings are valid and reliable. As data has been collected from a variety of sources to reflect alternative perspectives on the value of autonomy it is also possible to claim that the selection process was conducted objectively and with a view to reducing the incidence of biased interpretations and research outcomes.

Results

Legislation suggests that it is not uncommon for persons to worry about what might happen to them if they are no longer capable of making their own decisions. And based on the fact that a surrogate must act in their best interests their primary concern must be that in so doing they may not be loyal to them or to their wishes when they are themselves helpless to act. However, legislators are equally aware that a doctor’s self-proclaimed mission or purpose in life is to heal and/or care for the sick. They are also minded that medical professionals are required to make decisions and act in difficult situations when under pressure and that it is unreasonable to

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[36] The way we treat one another is derivative of our ideas about the significance of the human body and life

expect them to carry out their obligations fearing that they may be litigated against whichever way they decide things.

Accordingly, the issue of who decides and of how they decide what should happen to patients who suffer a loss of decision-making capacity has been debated since 1990 and the case of *Re F*, culminating in the recent enactment of the MCA. This conversation, concerning the doctor-patient relationship, was taking place at a time when the collective will sought constitutional protection of individual rights as a way to promote the various fundamental freedoms and liberty interests of all persons.[37] It was therefore apparent that an increased emphasis on patient autonomy in personal decision-making and respect for individual wishes based on values was upon us. The Act is an attempt to acknowledge this and to incorporate this perspective into law.

Initiatives that aimed to make respect for autonomy overriding in this context required the legislature to encourage competent patients to take steps in advance of a time when they might suffer from a loss of decision-making capacity and when decisions concerning their welfare might have to be made. Hence we have legal recognition of living wills or advance decisions. And, as priority is accorded to the advance decision of a competent patient, over what others may consider is in their best interests, the concept of precedent autonomy has become established within the legislative framework.

This means that paternalist intervention is preceded by the need to respect someone by means of giving them what they previously wanted. Essentially the legislature is saying that past decisions are important indicators of what the patient would want now when they are incompetent and unable to form a view contemporaneously. Treating someone in this way is the best way we have of respecting their autonomy and right to self-determination in the present. The problem is that, the concept, as currently defined and used under the MCA is given a fairly narrow window of opportunity to fulfil its purpose of empowering patients and of requiring others to respect their right to self-determination with regard to their own body and life.

However, it would seem possible to breathe new life into the concept of precedent autonomy if the values, beliefs and preferences that underpinned

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[37] For example, the enactment of the Human Rights Act 1998

the decisions of the patient could be identified, expressed and preserved, for future use, in a living will. The idea in disclosing ones values or value system in this way is that it would be regarded as a relevant written statement of the patient that could be used to inform a best interests treatment decision but it could just as well be used to inform a capacity assessment. Accordingly, an advantage in disclosing one's values over conventional advance decisions is that it might conceivably be incorporated into an advance decision or could be used by others to inform a wider range of treatment decision-making processes under the MCA based upon the contents of the patient's living will.

The problem is that although the MCA could support such an approach to decision-making I fear that a doctor as surrogate decision-maker might be inclined to prioritise the current wishes and feelings of a sentient but incompetent patient, which are by their very nature experientially valid, over the autonomously chosen critical interests of their former competent self. In doing so they would apply the test of best interests test in a way that suggests the right to autonomy is necessarily contemporary. As such I argue that the MCA is in need of reform if a values-based approach to decisions taken on behalf of formerly competent patients is to work well and be prioritised. In this respect I draw upon the work of Pellegrino and Thomasma, amongst others, to propose that if beneficence is not to triumph over autonomy that a fiduciary principle is needed to underpin the nature of a doctor's duty at both stage one and stage two of a treatment decision-making process to indicate where loyalty should lie in respect of formerly competent persons.

To state the case in support of a values-based approach to decision-making I draw on the work and theoretical perspectives of Kant, Mill, Raz, Dworkin and Beauchamp and Childress, amongst others. My purpose in doing so is to ensure that a competent person's legally protected right to choose or reject medical treatment is safeguarded, not lost or diminished by virtue of subsequent physical or mental incapacity or incompetence.[38]

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[38] *Re Guardianship of Estelle M. Browning, 568 So.2d 4*, para. 7