

AUTONOMY AND THE REFUSAL OF  
LIFE-PROLONGING THERAPY

by

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*Introduction*

During the past twenty years the principle of respect for autonomy has grown to considerable prominence in medical law and bioethics. It has been promoted as a counter to both physician and state paternalism, and requests for the refusal or abatement of life-prolonging therapy have been championed by euthanasia societies, cost-containment advocates, and liberal bioethicists. Mechanisms for the autonomous refusal of therapy, such as living wills and advance directives, together with health-care powers of attorney, proxies and surrogates, have all attached themselves to the principle of patient autonomy. These mechanisms are well-established in U.S. law and have found a foothold in medico-legal practice in the U.K. Whilst applauding demands for greater autonomy as part of a broader political demand for greater control over one's life, I shall, nevertheless, draw attention to some of the pitfalls in the formal mechanisms devised to advance autonomous refusal of therapy. First, the reduction of autonomy to therapy refusal will be questioned; second, mechanisms such as advance directives will be shown to be unsatisfactory means of expressing autonomous refusal; and third, the tendency to amalgamate autonomous refusal with surrogate decision-making will be questioned. However, this criticism of a formalistic approach to autonomous decision-making in health care is not designed to undermine the principle of autonomy or to protect physician authority, but rather to locate autonomous medical decision-making in a trusting relationship between carer and patient.

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*The Reduction of Autonomy to Therapy Refusal*

Appeals to autonomy have dominated recent discussions on health-care ethics, yet arguments about choosing therapy have been conducted solely in terms of an individual patient's ability to express a conscious refusal, or at least indicate in advance a surrogate capable of exercising that refusal. In 1992, the Appleton International Conference upheld the principle of autonomous patient refusal and recommended that in the case of a patient who has lost the capacity to make decisions but has given a valid advance directive to refuse treatment and/or has appointed a representative to make decisions about refusal of treatment, such directives and decisions should be respected by doctors and other health-care workers.<sup>1</sup> But there is more to the exercise of autonomy than the formal expression of refusal.

In April 1986, a 28-year-old American woman, Elizabeth Bouvia, successfully established her right to refuse therapy despite the fact that such a course was life-threatening. She was described as quadriplegic. Except for a few fingers of one hand and some slight head and facial movements she was immobile. In the majority of reports concerning her condition she was said to suffer from degenerative and severely crippling arthritis. She was in continuous pain. A tube permanently attached to her chest automatically dosed her with morphine which relieved some, but not all, of the pain and physical discomfort. She had previously sought the right to assisted suicide, requesting care in a public hospital while she intentionally starved herself to death, but the courts refused her request. However, when the state of her health declined to the point where she could not be spoon-fed without vomiting and nausea a drastic decision was taken. Noting the court's ruling against her suicidal intentions, the hospital authorities decided that when her weight loss reached a life-threatening level a nasogastric tube should be inserted, even though it was against her will and contrary to her express instructions. Acting on legal advice, Elizabeth Bouvia took her case to the California Court of Appeal where she sought "the removal from her body of a nasogastric tube inserted and maintained against her will and without her consent by physicians who so placed it for the purpose of keeping her alive

1 Appleton International Conference, "Developing Guidelines for Decisions to Forego Life-prolonging Medical Treatment", *Journal of Medical Ethics* 18 (1992), supplement.

through involuntary forced feeding".<sup>2</sup>

The Court ruled in her favour. In his twenty five page ruling, Associate Justice Edwin Beach said: "She has the right to refuse the increased dehumanising aspects of her condition created by the insertion of a permanent tube through her nose and into her stomach."<sup>3</sup> The question of passive euthanasia or assisted suicide was clearly ruled out when the Court stated that it was immaterial whether or not the removal of the tube caused her death: "Being competent, she has the right to live out the remainder of her natural life in dignity and peace."<sup>4</sup>

Having established her right to forego her life-sustaining therapy, however, a victory secured after a two-year long legal battle, Elizabeth Bouvia decided not to have the tube removed. The real issue was not whether she should live or die, but how she could control her destiny.

The court ruling and the media attention which focused on Elizabeth Bouvia's campaign for accelerated death reveal only a fragment of the tragic events leading to her request for the removal of life-prolonging therapy. The issue that was not addressed throughout the legal proceedings concerned Elizabeth Bouvia's motivation. Was she trying to express an autonomous decision to forgo attempts to prolong a life *she* had assessed as physically unendurable? Or was she responding in the only way open to her against longstanding societal prejudice against disability? This important distinction seems to have been ignored by many liberal advocates of a right to death. Paul K. Longmore points out that Elizabeth Bouvia had faced a life-time of social prejudice and discrimination against the disabled.<sup>5</sup> From childhood she had suffered from cerebral palsy; had been rejected by her parents; and then been penalised in education and employment when she had struggled to develop a productive life. Although she had obtained a degree, her training for a career was further penalised by discriminating Social Security regulations. When she requested physician-assisted suicide in a petition that was rejected in 1983, her disability was not the only reason: there were very severe personal stresses; she had become pregnant and miscarried; and experienced separation and divorce proceedings. Yet the three psychiatric

2 *Bouvia v. Superior Court* [1986] 225 Cal. Rplx. 297 (Cal. C.A.).

3 Edwin Beach, Associate Justice, quoted in *Medical Ethics Advisor* 7/4 (1991), 49.

4 *Supra* n.2.

5 Paul K. Longmore, "Elizabeth Bouvia, Assisted Suicide and Social Prejudice", *Issues in Law & Medicine* 3/2 (1987), 141-168.

professionals brought in by her attorneys simply concluded that it was her physical condition, her disability, which motivated her request for death, and consequently ignored the series of emotional blows. Having listened to the evidence the judge expressed the hope that Bouvia's case would "cause our society to deal realistically with the plight of those unfortunate individuals to whom death beckons as a welcome respite from suffering".<sup>6</sup>

It is important to recognise a distinction between the social background to Elizabeth Bouvia's petition and the issue presented to the courts. The courts, upholding respect for the principle of autonomy, were interested in whether a rational decision had been taken, one based on a realistic appraisal of her situation (as opposed to an impulsive and emotional reaction). But those who assessed her, argues Longmore, had no experience of disability, and had a prejudice that no one who is almost totally paralysed and in need of a respirator can experience a life that is worth living. This prejudice disposed those around her to see autonomous decision-making purely in terms of the right to forego life-sustaining therapy and consequently to ignore the social context in which the requirements for a productive and meaningful life had been withheld.

In some recent decisions on autonomous refusal of therapy idealised models of autonomy have been borrowed from political discourse and applied to health-care with devastating results. The policy of restoring "autonomy" to mental patients in the United Kingdom over the past decade is one unfortunate example. Releasing patients from institutional confinement without adequate community support has not enhanced their capacity for autonomy. Instead, it has caused hardship and needless distress — thus illustrating the fact that autonomy is neither developed nor protected by the withdrawal of societal support. Indeed, a cynic might argue that the eminence of autonomy in recent years has less to do with genuine concern with the liberty of the patient than with the need to restrain costs associated with what some perceive as "over treatment" or burdens upon the taxpayer. In the political context liberal individualist values have stressed the freedom of persons from state authority and the restraint of tyrants. In the political sphere restraint of government has been the hallmark of liberal values. In this respect medical paternalism has been presented as an unwarranted extension of political

6 *Supra* n.5, at 159.

power. Consequently, attempts to roll back the power of the state, as well as that of doctors and health-care professionals, have been welcomed by liberal theorists. Thus with government withdrawal from public welfare commitments the right to opt out of state-run health provisions has been presented as an extension of personal liberty against paternalistic intervention. But while freedom and autonomy may flourish with the withdrawal of political tyranny, patient autonomy and physician authority is not a zero sum game with winners and losers. The concept of autonomy in health care is embedded in the relationship between carer and patient. This actually recognises that autonomy has a wider meaning in the moral sphere than it does in the political. As George J. Agich argues:

The abstract liberal concept of autonomy has its proper place in the legal political sphere, where protection of individuals from tyranny and oppression by powerful others is rightly defended, but not in the moral life, where a fuller conception is required, one that acknowledges the essential social nature of human development and recognises dependence as a nonaccidental feature of the human condition.<sup>7</sup>

The goal of autonomy in the provision of health-care, especially in Agich's account of the needs of patients requiring long-term care, is not reducible to the removal of obstacles and state interference. It may also require a maximisation of options and community support. Dependence is not antithetical to autonomy in the moral sphere, where autonomy might well be compatible with dependence upon a nurse or helper. There has been too much emphasis on resistance to unwanted care and paternalistic abuse and all too little recognition that, for many patients, including the very young and the old, some form of dependence is the condition upon which autonomous decision-making rests. Agich's analysis of autonomy is important in this respect: although relevant to the political and legal sphere, the abstract liberal concept of autonomy should not be extended uncritically into the moral sphere and limits on the ideal should include recognition of "the essential historical and social nature of persons", especially in "the development aspects of becoming and being a person".<sup>8</sup>

Appeals to an individual's capacity for autonomous decision-making are frequently made against a background assumption that the individual

7 George J. Agich, "Reassessing Autonomy in Long Term Care", *Hastings Center Report* (Nov./Dec. 1990), 12-17, at 12.

8 *Supra* n.7, at 12-13.

can be detached from the wider social context. This assumption is also bound up with a form of moral individualism in which morality is determined purely by an individual's subjective desires. But decisions in favour of therapy abatement are not strictly subjective; they require the complicity of the medical staff — which is not a private matter. The decision to abate therapy requires at least two people and a complicit society to make it acceptable. Health-care professionals are under the obligations, which society requires of them, to maintain care and intervene benevolently. This cannot be rejected lightly, for morality is not reducible to the arbitrary decisions of either individual patients or doctors.

The fact that there is more to autonomy than the right to refuse has not been fully appreciated by many philosophers and lawyers who have expended large amounts of energy in arguments for the withdrawal of therapy and accelerated death. Fortunately the courts have recognised that arguments for the right to an early death do not exhaust the range of morally relevant considerations. That there is more to autonomy than the right to an early death was recognized in a decision reached by the Nevada Supreme Court, following the death of Kenneth Bergstedt in 1991.

Kenneth Bergstedt was a 31-year-old ventilator-dependent quadriplegic who was cared for by his father. When facing the imminent death of his father he petitioned the court for the withdrawal of life-sustaining therapy. But whilst the legal proceeding dragged on Bergstedt died in circumstances which suggested that his death had been planned. The toxicology report revealed a high level of barbiturates in his system and the respirator clamp had been unfastened so that he could remove the tube from his mouth. Nevertheless, the Court went on to issue a “decision” in order to “provide guidance to others who may find themselves in similar predicaments”.<sup>9</sup> The Court expressed a “state interest” in preserving life, but recognized that an individual’s “right to decide” will “generally outweigh the state’s interest in preserving life”,<sup>10</sup> even if the condition is not terminal. But, most important, the Court required that all competent patients be informed of available health-care alternatives before ending life-sustaining therapy. This is very important because it maintains the principle of autonomy in decisions to abate

9 *McKay v. Bergstedt* [1980] 801 P2d 617 (Nev. Sup. Ct.) in Ian Kennedy and Andrew Grubb, *Medical Law, Text with Materials* (London: Butterworth, 1994, 2nd ed.), 1271.

10 *Supra* n.9.

therapy, while isolating arguments based exclusively on appeals for the right to an early death. Too frequently, autonomy is paraded in slogans bound up with the right to die. The Nevada Supreme Court, in this decision, placed autonomy back in the centre of public interest.

A precedent which might have influenced the Nevada Supreme Court was a ruling by the Supreme Court in the State of Georgia on a quadriplegic, Larry James McAfee, who pleaded for the discontinuation of ventilatory support. After winning his case, and repeatedly insisting that he would exercise his right-to-die, he was offered residence in various institutions with the intention of making his life more productively tolerable. He consequently chose to remain alive.

At the age of 34 McAfee was rendered ventilator-dependent after a motor-cycle accident. When his insurance benefit of \$1 million ran out and he could no longer employ home attendants he was obliged to enter a nursing home. He then decided that his life was not worth living. He tried to turn his ventilator off but could not stand the feeling of suffocation. He petitioned the courts unsuccessfully for permission to be sedated while someone switched off his ventilator. However, he acquired a delay mechanism which would enable him to turn off the ventilator and then allow time for sedation to take effect. The court ruled that this was acceptable and the judgement was based on his rationality and state of disability. The case aroused publicity and McAfee obtained support from disability rights activists. When McAfee reversed his decision it was revealed that what he really wanted was social and economic independence — autonomy — not death. A disability organisation arranged for him to be trained for employment in voice-activated computers. But his Medicare benefits ran out, and Medicaid were unwilling to pay for the nursing costs to meet his needs. It appears that in this case respect for the principal of autonomy did not extend to the provision of resources that would make a reconsideration of therapy abatement worthwhile. The background to the court ruling indicates that, as in the case of Elizabeth Bouvia, social factors, rather than disability, played a role in McAfee's request for an early death.

#### *Autonomous Refusal and Advance Directives*

The potential for dramatic decision-reversals has not been fully appreciated by the architects of formal expressions of autonomous refusal, such as living wills and advance directives. For despite their popularity

with the media and the bioethicists, living wills have not been enthusiastically accepted by those who are supposed to benefit from them. Opinion poll surveys have indicated that few people actually make them out.<sup>11</sup> Even when they are made out many physicians are reluctant to follow them.<sup>12</sup> John F. Robertson, in a critical commentary on the living will juggernaut, speaks of a distrust and ambivalence among ordinary people and policy-makers. He sees the roots of this distrust in "conceptual confusions and contradictions that inhere in the use of an advance directive to control a future situation".<sup>13</sup> These might collectively be described as "the new persons argument". For example, a healthy person signs an advance directive and some time later succumbs to Alzheimer's disease, with little memory or continuity with her former self. She has no recognition of her friends or family and no awareness or recollection of previous decisions. Should the advance directive signed by her former self be put into effect? It might be said that in such cases, which involve a radical break in psychological continuity, we should recognise that we are confronted with a new person. If so, the former person should not be allowed to harm or cause the death of the new person. Self-determination would no longer prevail as the old self has gone. The former person is no more and will never even know if her wishes were carried out or violated. It might even be said that the best interests of the new person lies in a continuation of life-prolonging therapy. Close friends and relatives may experience the loss of the old person as a catastrophe, but this is not experienced by the new person whose apparent needs are for comfort and nourishment. Such examples indicate a level of conflict between honouring an advance directive issued by an autonomous person and serving the best interests of the incompetent new person. It is not clear, argues Robertson, that a prior directive made by a competent person is the most accurate indicator of a person's interest

- 11 Linda L. Emmanuel and Ezekiel J. Emmanuel, "Does the DNR Order Need Life Sustaining Intervention?", *The American Journal of Medicine* 86 (1989), 87-90.
- 12 Joan M. Teno, Joanne Lynn, Russell S. Phillipps, Donald Murphy, Stuart J. Youngner, Paul Bellamy, Alfred F. Connors Jr., Norman A. Desbiens, William Fulkerson, William A. Kraus, "Do Formal Advance Directives Affect Resuscitation Decisions and the Use of Resources for Seriously Ill Patients?", *The Journal of Clinical Ethics* 5/1 (1994), 23-37.
- 13 John F. Robertson, "Second Thoughts on Living Wills", *Hastings Center Report* (Nov./Dec. 1991), 6-9, at 7.



when she becomes incompetent. There is a different framework in the latter case; the rational standpoint on which the prior decision was made is missing. The values and interests of the competent have no meaning to the incompetent and are distinct from them. It is the competent person who does not want to be maintained in an incompetent state; we cannot speak authoritatively of the wishes of the incompetent, which do not necessarily rest on any rational basis. "Yet the premise of the prior directive", says Robertson, "is that the patient's interests and values remain significantly the same".<sup>14</sup> But we cannot know that this is so. What we do have, however, is an increasing number of cases, like Bouvia and McAfee, where a strongly held preference is freely reversed. The difference is that in these cases the authors were competent at the time of the reversal. Merely because incompetents cannot express a reversal does not guarantee that their interests, or their preferences, remain identical with their previous competent state.

A rebuttal of the new person argument has been put forward by Norman L. Cantor, who argues that the original terms of an autonomous advance directive should have priority over later considerations. Says Cantor: "the *potential* changeability of people's feelings should not be a basis to bar future-orientated directives".<sup>15</sup> Cantor draws a parallel between the living will and other legal dispositions, pointing out that the "law does not withhold enforcement of future-orientated dispositions of property by will, irrevocable trust, or contract, even though the disposer's inclinations might change over time".<sup>16</sup> The original terms of the advance directive, argues Cantor, should not be overturned without additional evidence indicating a need to revoke them: "In the context of advance medical directives, it should at least be assumed that a directive maker's wishes persist over time unless there is some showing to the contrary."<sup>17</sup> Cantor dismisses the objection that one might not be capable of imagining the reality of a future state of incompetency, although he does recognise that it ought to "impel some serious deliberations (by the declarant) about the content of an advance directive".<sup>18</sup> These assurances presuppose that an advance directive is

14 *Supra* n.13.

15 Norman L. Cantor, *Advance Directives and the Pursuit of Death with Dignity* (Bloomington and Indianapolis: Indiana University Press, 1993), 27.

16 *Supra* n.15.

17 *Supra* n.15.

18 *Supra* n.15.

properly thought out and drawn up in the context of close cooperation between the doctor and the health-care agent, with the possible assistance of experienced counsellors. This procedure will be expensive and time-consuming for medical staff. The advance directive is certainly no substitute for a close doctor-patient relationship.

Yet no amount of counselling and preparation would seem to remove the potential for conflict between prior personal choice and immediate well-being. From the standpoint of the physician, there may be an obligation to respect the autonomous wish of a former competent patient. Yet this may come into conflict with professional duties to provide what is recognised as appropriate therapy to a patient who has succumbed to serious impairment. Cantor offers two examples which test the limits of advance directives. First, he considers an advance directive specifying no life-saving treatment if mentally impaired, whose author later succumbs to mental impairment and, apart from occasional periods of alertness, remains incompetent, although enjoying relative comfort in a nursing home. Should this patient be treated for pneumonia? His second example is that of a vitalist with terminal cancer who ends up mentally incompetent and in extreme pain. Should every effort be employed to sustain life? (Or to consider a slightly different example: a person signs an advance directive indicating no therapy in the event of a degenerative condition such as Alzheimer's disease. But in the early stages of the disease the patient requests treatment. Should the directive be disregarded? Suppose it is, and the patient continues to deteriorate: should it always be the most recent decision that is regarded as valid?) In these cases should advance directives be revoked or merely suspended? These problems suggest a need for constant attention to the status of the document in the patient's mind. But when the mind is impaired, such attention is ruled out. What we are left with is a potential conflict for the medical team between honouring the advance directive and providing what is regarded as professionally appropriate treatment in the patient's best interest.

One objection to the new person argument may lie in an appeal to the wholeness of the self, where it is insisted that the self has a unity that exists over one's entire life, and that if previously competent persons have a history of preferences and values they should be treated — when incompetent — as still having those values. It might be argued that being competent and being incompetent are stages in the same person's life, and that it is only a metaphorical way of speaking when we say "she

isn't the same person any more". If this is the case, then it could be said that if we are confronted with a single existence we should place greater weight on decisions taken when competent. This, however, is a weak argument which simply overlooks the fact that people *can* radically change their interests and values throughout their lives. At the very least any course of action based on an appeal to the autonomy of persons must respect the fact that their interests may be revised.

It must be acknowledged that society does honour wishes and respect the prior dispositions of those who have lost competence. Losing competence is not a basis for allowing others to do to one as they think fit. It is recognised that a being can be harmed even if the harm cannot be experienced or reflected upon. We do not permit experiments upon incompetent patients. To a certain extent these attitudes towards incompetent patients, and the values they embody, are similar to the way in which society honours the recently deceased. These values are, as Cantor argues, bound up with notions of post-competent dignity and respect where a prospective personal image is of considerable importance. Sympathy for the person who makes a prior declaration that he or she would not wish to be maintained alive in a post-competent state is a reflection of our respect for the notion of having a life-time mastery of one's body. Yet it is hard to reconcile our respect for self-mastery and the protection of one's image of life with proposals to withhold life-prolonging therapy from a life that is pleasantly but unknowingly senile.

It is this potential for conflict between personal choice and the best interests of the incompetent person which weakens the appeal to autonomy in advance directives which specify abatement of life-sustaining therapy. Admittedly it is difficult to verify or assess the extent of this conflict, as in most of these cases the patient remains incompetent until death. But there is plenty of anecdotal evidence of patients being treated, despite a contrary directive, and then recovering with gratitude. Perhaps the most informative thing that can be said about advance directives is that they are a device for measuring a person's interests, not an expression of the sort of certainty which is a characteristic of the will of a deceased person.

Even if these practical problems with advance directives could be resolved, the objection remains that autonomy is not always the highest virtue, and that autonomous refusal may have to be weighed against a presumption in favour of life, especially in cases involving an alleged

change of mind, as indicated by James F. Childress's borderline example:

A twenty-eight-year-old man [who] decided to terminate chronic renal dialysis because of his restricted life-style and the burdens on his family – he had chronic diabetes, was legally blind, and could not walk because of progressive neuropathy. His wife and physician agreed to provide him with medication to relieve his pain while he died and agreed not to put him on dialysis even if he requested under the influence of uraemia, morphine sulphate, and Ketoacidosis (the last resulting from cessation of insulin). While dying in hospital, the patient awoke complaining of pain and asked to be put back on dialysis. The patient's wife and physician decided to act on the patient's earlier request that he be allowed to die, and he died a few hours later.<sup>19</sup>

Childress argues that he should have been put back on dialysis where it could then have been determined whether he had autonomously revoked his earlier decision. If it was then deemed that his earlier decision was uppermost they could have proceeded with more confidence. "Present revocation", argues Childress, "takes priority if it is autonomous".<sup>20</sup>

Of course if a patient becomes incompetent through dementia and is so demented that s/he cannot understand the choices offered and the potential consequences of any choice then it is not an autonomous revocation. In such cases, argues Cantor, the prior directive should apply: "The ravings of a deeply demented patient ought not be permitted to override an advance directive."<sup>21</sup> Quite obviously Cantor recognises that revocation on these terms would make a mockery of the earlier decision. But a more modest course, involving a temporary suspension of the advance directive, is preferable. Ravings can be interspersed with periods of lucidity which are not always identified by busy health-care staff. A temporary suspension would allow time to consider whether an autonomous revocation was being made, and it would also alleviate the anxieties of health-care staff who are reluctant to withhold treatment from those whose condition requires it.

Why is it that there is concern, in cases of this kind, over which decision counts? Surely both were taken by the agent concerned. One obvious answer is that it is the truly autonomous decision that is being sought. But there is another answer, and one which reveals the impor-

19 James F. Childress, "The Place of Autonomy in Bioethics", *Hastings Center Report* (Jan./Feb. 1990), 12–17, at 14.

20 *Supra* n.19.

21 *Supra* n.15, at 85.

tance of a presumption in favour of life in doubtful circumstances: a decision in favour of life-prolongation can always be annulled if it turns out that this was not autonomously desired by the patient. Steps taken to end a life, however, cannot be revoked if it later turns out that this was not autonomously desired.

### *Autonomy and Surrogacy*

Some of the dangers of the abuse of autonomous refusal are beginning to emerge. A serious problem concerns the employment of surrogates to express a patient's "autonomous" choice. There are, for example, problems about who is an appropriate surrogate. Although it is accepted that surrogates should be close family members there are many who do not live in "recognized" families, such as members of the gay community. There is also what Americans describe as "the Florida syndrome", where elderly retired parents have lost contact with their offspring, although the latter may be called upon to make decisions without appreciating their parent's desires regarding therapy options. A similar problem occurs if it is the parents in such circumstances who are called upon to make decisions on behalf of estranged offspring.

Some crucial distinctions need to be addressed when formulating guidelines for surrogate decision-making. One case involved a U.S. court ruling concerning a severely mentally retarded cancer patient, Mr. Storar, whose mother's request for the discontinuation of blood-transfusions was turned down.<sup>22</sup> Mr. Storar had never been competent and the Appeal Court refused his mother's request to abandon blood transfusions for his cancerous condition, setting limits to surrogacy and stressing that no one, neither parent nor sibling, should decide that an incompetent should bleed to death. The basis of the court's decision was that because of Mr. Storar's retardation it was impossible to know what his wishes would have been before therapy for cancer was applied. "The court's decision", says Robert Zussman, "involves an important legal principle. It distinguishes between formerly competent patients and never competent ones like Storar."<sup>23</sup>

In recent years U.S. courts have operated with three distinct stan-

22 Re John Storar, [1981] 420 N.E. 2d 64 (N.Y.C.A.).

23 Robert Zussman, *Intensive Care: Medical Ethics and the Medical Profession* (Chicago: Chicago University Press, 1992), 175.

dards for surrogate decision-making on behalf of patients who have become incompetent. First are subjective standards which require that the surrogate seek to “discover and effectuate the patient’s own preferences expressed before the patient lost decision-making capacity”.<sup>24</sup> This would involve attempts to discover the patient’s known preferences and would rely on oral statements made by the patient before losing competence. The second set of standards are more hypothetical: they are the substituted judgements whereby the surrogate is required to “make the best approximation of what the patient would or would not have wanted”.<sup>25</sup> While the subjective standard asks, “What did the patient decide before losing decision-making capacity?” the substitute judgement standard asks, “What would the patient decide if the patient were able to decide?” The third standard, which is employed in the U.K., where it would seem that the courts have a better grasp of moral complexity than liberal theorists, is an appeal to the best interests of the patient. Unless the surrogate is merely implementing the known wishes of the patient, this is clearly quite unrelated to the principle of autonomy. While it is clear that patients like Mr. Storar, who have never been competent, are ineligible for subjective and substitute standards, it is also questionable whether either the subjective standard or the substitute judgement standard can function as the autonomous preference of a patient no longer capable of decision-making. Kathryn A. Koch *et al* suggest that the belief that substitute judgement represents patient autonomy is a “figment of our imagination” and argue that the best interest standard, based on an assessment of benefits and burdens, should prevail.<sup>26</sup> Accordingly they maintain that there may be times, in the absence of any clear patient preference, when medical knowledge can re-assert itself against the wishes of a family, when the medical facts become so clear that decisions about level of care should rest with the doctors. Subjective standards and substitute judgements have been rejected in English law, which favours the “best interest” test, where the medical carers of an incompetent patient make decisions in the patient’s best interests in accordance with a responsible and competent body of relevant

24 See Alan Meisel, “A Retrospective on Cruzan”, *Law, Medicine & Health Care* 20/4 (1992), 340–353, at 342.

25 *Supra* n.24.

26 Kathryn A. Koch, Bruce W. Meyers, Stephen Sandroni, “Analysis of Power in Medical Decision-Making: an Argument for Physician Autonomy”, *Law, Medicine & Health Care* 20/4 (1992), 320–325.

professional opinion. Despite objections from liberal theorists who see "best interest" tests as a barrier to full-blown patient autonomy, they are vastly superior to subjective standards and substitute judgements, inasmuch as they function within the parameters of morally responsible professional standards. Serious doubts concerning the employment of surrogates to act on behalf of incompetent patients were expressed in the conclusion of the House of Lords Select Committee on Medical Ethics:

... the appointment of a surrogate to act for a patient who, through mental infirmity, has never been competent to form a reasoned judgement, seems to stretch the concept of patient autonomy to breaking point. This would also be the case if the patient were a carefree young adult, living solely in the present, with no thought for the morrow and no true understanding that life may change for the worse, and having no taste or capacity for addressing the wider and deeper issues raised by grave illness, inability to communicate, destruction of personal dignity and erosion of the quality of life.<sup>27</sup>

There should be serious concern over a tendency to amalgamate surrogate decision-making with autonomous refusal. It may be necessary in such cases to appoint a surrogate to act in a patient's best interests, with powers to refuse therapy. But the decision to authorise a surrogate cannot be based on an appeal to patient autonomy and self-determination. The introduction of a legal fiction that autonomous decisions can be made by others is incompatible with the principle of autonomy. Whatever the moral value of surrogacy arrangements may be, they do not derive their legitimacy from an extension of principles regarding autonomy. What is missing in most of the surrogate decision arrangements is preservation of the patient's agency. This, by definition, is a problem if the patient is incompetent, which is a state where the capacity for agency is lost. Autonomy cannot be surrogated and we have to resort to the employment of mechanisms for making the *right* decision. It may not be a question of obtaining an accurate account of the patient's wishes, but one of formulating the right decision.

27 *House of Lords Select Committee on Medical Ethics* (London: HMSO, 1994), vol. I, p.55.

*Conclusion*

Autonomous decision-making over therapy options is not reducible to the refusal of unwanted medical intervention. This is a myth that has been imported from questionable assumptions in political economy, and is of little benefit to medical practice and the sometimes agonizing decisions which have to be taken by patients and their relatives. An individual's right to therapy abatement can be protected from abuse only in the context of a full understanding of autonomous choice; not merely the right to refuse, but the opportunity to receive assistance and consider alternatives. Limits are also required on the role of the surrogate in the refusal of therapy. Policies endorsing therapy abatement and exercise of the right to forego life-sustaining therapy should carry cast iron guarantees that they will not be disadvantageous to the poor and undereducated members of society. It should also be noted that fears of unlimited life-prolongation have been greatly exaggerated. In an atmosphere of governmental indifference to the plight of the sick, with the notion of welfare tuned to market forces, there is a danger that self-determination can have a restricted meaning; the option of death in the context of an underfunded health service. This may not be the time to campaign for the right to refuse therapy, but rather the time to campaign for improvements to existing therapy.