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ARTICLES

AUTONOMY, LIBERTY, AND MEDICAL DECISION-MAKING

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I. INTRODUCTION

A central tenet to much ethical argument within medical law is patient autonomy.[1] Although we have seen a welcome move away from a system governed by largely unchecked paternalism, there is not universal agreement on the direction in which medical law should advance.[2] Competing concerns for greater welfare and individual freedom, complicated by an overarching commitment to value-pluralism, make this a tricky area of policy-development.[3] Furthermore, there are distinct understandings of, and justifications for, different conceptions of autonomy.[4] In this paper, we argue that in response to these issues, there has been a failure by the courts properly to distinguish political concepts of liberty and moral concepts of autonomy.

English medical law demands non-prejudicial deference to patients' reasons for giving or refusing consent to treatment, creating a practical system of moral value-pluralism.[5] Whilst this is not intrinsically problematic, it creates problems in applying principles such as autonomy, which are often bound to ideas of rationality. We therefore give an account of what respecting autonomy means and how it contrasts with the protection of other related and important concepts. This enables us

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[1] K. Veitch, *The Jurisdiction of Medical Law* (Aldershot, 2007).
[2] M. Brazier, "Do No Harm – Do Patients Have Responsibilities Too?" [2006] C.L.J. 397.
[3] M. Dunn and C. Foster, "Autonomy and Welfare as *Amici Curiae*" (2010) 18 Medical Law Review 86.
[4] G. Dworkin, *The Theory and Practice of Autonomy* (Cambridge 1988).
[5] *Re T (Adult: Refusal of Treatment)* [1993] Fam. 95; *In Re MB (Medical treatment)* [1997] 2 F.L.R. 426; *Ms B* v. *An NHS Hospital Trust* [2002] 2 All E.R. 449; Mental Capacity Act 2005, section 1(4).

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to critique the existing legal picture. Although we are content with the general direction of medical law in this area, we discuss causes for concern with the current situation. Our primary criticism is that there may be an excessive commitment to ostensible rather than substantive protection of autonomy. We also suggest that the proper demands of respecting an individual patient's values, whether or not the patient is able to act autonomously,[6] may not be fully acknowledged. We map these concerns by exploring developments in medical jurisprudence and the Mental Capacity Act 2005. Our analysis exposes troublesome issues, but we argue that positive changes can be effected within the existing system. Legal change is not needed provided that judges, policy-makers, and practitioners understand the import of their actions and the bearing of existing principle.

II. Autonomy: Government within a Shared System

Autonomy is a familiar concept within legal, moral, and political philosophy.[7] Within medical ethics and healthcare law it has become deceptively familiar. While it has, in many respects, attained a supreme status,[8] there is considerable variation in *how* the concept is understood.[9] Normative concerns regarding an excessively paternalistic medical profession, supported by an excessively deferential judiciary, gradually led to a radical change in practice, as explored below.[10] But what does autonomy mean and what is its importance within a regulated social and healthcare system?

At its most simple, autonomy denotes self-government. In this basic sense, it is not so much a normative concept as an empirical question: we do not know *ex ante* that (or how much) autonomy is good. Rather we ask whether autonomy exists in any situation: *is* a person directing her action? If yes, she is being autonomous, if no, she is not. This does not tell us that she should be self-governing. Whether it is good that people govern themselves, or to what extent they should do so,

[6] Decisions made on behalf of incapacitated patients by third parties still must reflect the patients' particular system of values, beliefs, wishes, and feelings, and account for factors that would bear on the patients' own decisions were they able to make them: Mental Capacity Act 2005, section 4(6).

[7] Key texts include: O. O'Neill, *Autonomy and Trust in Bioethics* (Cambridge 2002); C. MacKenzie, N Stoljar (eds.), *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self* (Oxford 2000); J. B. Schneewind, *The Invention of Autonomy: A History of Modern Moral Philosophy* (Cambridge 1997); Dworkin, note 4 above; R. Lindley, *Autonomy*, (Basingstoke 1986); J. Raz, *The Morality of Freedom*, (Oxford 1986); H. G. Frankfurt, "Freedom of the Will and the Concept of the Person" (1971) 68 Journal of Philosophy 5.

[8] M. Brazier, "Do No Harm", note 2 above: much of Brazier's concern is directed at what we label "liberty" rather than "autonomy".

[9] J. Coggon, "Varied and Principled Understandings of Autonomy in English Law: Justifiable Inconsistency or Blinkered Moralism?" (2007) 15 Health Care Analysis 235.

[10] Lord Woolf, "Are the Courts Excessively Deferential to the Medical Profession?" (2001) 9 Medical Law Review 1.

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are many-layered questions. Differing problems present themselves. For example, there are concerns about what authority the 'self' in a self-governor has: is a young child capable of autonomy, or is she too ignorant and irrational *meaningfully* to self-govern? Is being autonomous an absolute matter, meaning either one is or is not autonomous, or is it graded or context-specific, meaning one can be more or less autonomous? Is there a special normative concern due to something, such as an adult human being, simply by virtue of her capacity for autonomy? If so, does it apply also to someone with the *potential* to become autonomous? Consideration of such matters has dominated ethical debates on doctor-patient interactions, leading to more practically focused normative questions. For example: how much information should a doctor give a patient about a proposed intervention?[11] Does a patient have a right to remain ignorant of the detail of a medical condition?[12] Ought a patient to be able to demand some intervention, even if a medical expert considers it to be harmful?[13] The handling of the radically distinct normative matters at issue in such questions is not always adequately nuanced to deliver satisfactory analyses. Thus, we need to clarify what our focus on autonomy entails to enable meaningful discourse.

Jennings[14] and Griffin[15] highlight the important distinction between autonomy as it refers to matters concerning the freedom of the will, and as it relates to political freedom within a society to act unencumbered by the interference of third parties or the State.[16] Adopting their approaches we distinguish the concepts terminologically. For our purposes, *autonomy* relates to free will, so an "autonomous agent" is someone with free will, and *liberty* relates to freedom to act without the interference of a third party. Thus, a prisoner may enjoy a high level of autonomy whilst having extremely limited liberty, and a person with a low "mental age" will have a low level of autonomy whilst potentially having a great deal of liberty. Importantly, interference with liberty can, in principle, obtain in omissions as well as actions. For example, although the controllers of a public building with no wheelchair access have not *actively* interfered with the liberty of wheelchair-users to

[11] J. Miola, "Autonomy Rued OK?" (2006) 14 Medical Law Review 108; S. Devaney, "Autonomy Rules OK" (2005) 13 Medical Law Review 102; A. Maclean, "The Doctrine of Informed Consent: Does it Exist and Has it Crossed the Atlantic?" (2004) 24 Legal Studies 386.

[12] J. Harris and K. Keywood, "Ignorance, Information and Autonomy" (2001) 22 Theoretical Medicine and Bioethics 415; M. Häyry and T. Takala, "Genetic Information, Rights, and Autonomy" (2001) 22 Theoretical Medicine and Bioethics 403.

[13] D. Gurnham, "Losing the Wood for the Trees: Burke and the Court of Appeal" [2006] 14 Medical Law Review 253.

[14] B. Jennings, "Autonomy" in B Steinbock (ed.) *The Oxford Handbook of Bioethics* (Oxford 2007).

[15] J. Griffin, *On Human Rights* (Oxford 2008).

[16] This distinction can be traced back to Berlin's celebrated distinction between the concepts he labelled positive and negative liberty: I. Berlin, "Two Concepts of Liberty" in I. Berlin, *Four Essays on Liberty* (Oxford 1969).

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enter, there *is* nevertheless an interference with liberty. Interference with liberty requires some form of agency, and, as is the case at law, reasonable provisions to support liberty are not limited just to "negative obligations" simply to leave people alone.[17]

Conflation of, or disregard for the difference between, autonomy and liberty cause conceptual flaws in analysis. This presents itself markedly when reference is made to ideas based on Kantian autonomy[18] as something that can be straightforwardly juxtaposed with Millian liberty.[19] In some respects this is perplexing, not least as Mill introduces *On Liberty* by saying:

> The subject of this Essay is not the so-called Liberty of the Will, so unfortunately opposed to the misnamed doctrine of Philosophical Necessity; but Civil, or Social Liberty: the nature and limits of the power which can be legitimately exercised by society over the individual.[20]

The two approaches can be distinguished by reference to the crux of concern that each has. Those interested in (Kantian) autonomy are concerned with the essence of a decision and how it is reached. Those interested in (Millian) liberty are concerned that a decision is made by the person whose right it is to make it, be that an individual on her own behalf or a third party deciding for her, rather (directly) than the rationality underpinning it.[21] A concern with both autonomy and liberty is appropriate, but they are not usefully conflated.

This is of interest to our legal analysis insofar as the questions become ones of *political*, as opposed to purely moral, philosophy. Where Kant is speaking to the metaphysics of the free will, it may seem odd that his concerns are relevant, but it is clear that in contemporary political philosophy generally, and medical law particularly,[22] there is what Geuss describes as a "strong 'Kantian' strand",[23] or in Gray's terms a pursuit of "the ideal of rational consensus".[24] Though their projects are markedly different, Geuss and Gray assume a Hobbesian perspective as the place from which to voice dissatisfaction with the dominance in political philosophy of (as they see it) misplaced faith in the relevance, applicability, and potency of such unitary, 'rationalised',

[17] Griffin, *On Human Rights*, note 15 above, pp. 166–7.
[18] I. Kant, *Groundwork of the Metaphysics of Morals*, edited by M. Gregor, (Cambridge 1998).
[19] J. S. Mill, *On Liberty*, edited by E. Alexander, (London 1999).
[20] *Ibid.* at p. 43.
[21] The distinction drawn here is simplified but is useful for illustrative purposes. We accept that a theory of legitimate liberty *can* entail a concern with rationality in order to assess who should be afforded liberty, *and* to assess whether the liberty is warranted in respect of any given action: consider Raz, *The Morality of Freedom*, note 7 above. As we argue below, it is proper that the law concern itself with both liberty and autonomy but, at this stage, we are drawing out the differences between the concepts.
[22] K. Veitch, *The Jurisdiction of Medical Law* (Aldershot 2007).
[23] R. Geuss, *Philosophy and Real Politics* (Princeton 2008), p. 1.
[24] J. Gray, *Two Faces of Liberalism* (Cambridge 2000), p. 1.

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abstract theorising, typified most forcefully for them in Rawls' influential theory of justice.[25] The effect of conceptualising (something approximating) the Kantian abstraction of a person, deducing what kind of rights, obligations, etc., it would have, and then formulating concepts of the legitimate State or laws and institutions around these is argued to be problematic. This is practically so because people in the world are not the concepts under discussion, and theoretically so because it denies the type of moral pluralism that is evident in the world that the theory would be 'applied' in. By wedding autonomy with rationality, as Kantian theory does, and then wedding *this* to prescriptive social norms, we leave ourselves with a concept that is unassailably entrenched in an exclusive rationality. There are two associated effects of this, which are the root of problems in the law on mental capacity. First, a practical truth is created about what choices may be *deemed* free, hinting towards paternalistic concerns that people be free only to do right, and political systems and legal mechanisms instituted to ensure this. In this regard, Gray's fears (unsurprisingly) echo those of Berlin.[26] Tensions arise regarding the extent to which people should be free to act 'irrationally' and how rationality itself is anyway established. Second, because theories based on 'rational consensus' trace back to a unitary and exclusive moral theory, they serve, in Gray's view wrongly, as practical denials of moral pluralism. They hold a singular ethic to be *the* morally and socially desirable end to be sought by governments and 'rational citizens' alike.

These effects are tempered when we look at the practical legal reality, but their urgency should not be underestimated. Already the common law has developed the category of "vulnerable adult" who meets the functional test for capacity (discussed below) but is denied decision-making power in order that 'more rational' decisions may be effected.[27] And, in less organised fashion, case law more widely betrays 'Kantian' rationality's employment as the basis of denials of decision-making capacity.[28] It is reasonable to suppose[29] that Lord Donaldson MR's celebrated statement that the law on decision-making should look to *capacity* rather than *rationality*[30] is born of a concern to protect plural, incommensurable moral values that exist amongst the population, and to safeguard people from excessive interference in their decision-making. Yet this formalised 'stand-offishness' remains at odds

[25] J. Rawls, *A Theory of Justice – Revised Edition* (Oxford 1999).
[26] I Berlin, "Political Ideas in the Twentieth Century," in Isaiah Berlin, *Four Essays on Liberty* (Oxford 1969); See also M Powers, "Bioethics as Politics: The Limits of Moral Expertise" (2005) 15 Kennedy Institute of Ethics Journal 305.
[27] M. C. Dunn, I. Clare, A. Holland, "To Empower or to Protect? Constructing the 'Vulnerable Adult' in English Law and Public Policy" (2008) 28 Legal Studies 234.
[28] Coggon, note 9 above, especially pp. 246–251.
[29] As suggested by an anonymous reviewer of this paper.
[30] *In Re T (Adult: Refusal of Treatment)* (1993) Fam. 95 at 116–117.

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with concerns for the welfare of the vulnerable, and has not been consistently applied.[31] It is hard to find a principled *and* soundly applicable theory that permits plural views *and* non-arbitrarily accommodates care for the 'genuinely incompetent' (for want of a better term). Where theories suggest that the bedrock of privileged decision-making is rationality, and the derivation of normative protection of human agents is their rationality, it proves difficult to avoid – yet still to reconcile – conflicts between Kantian-type appeals to autonomy as rationality and Millian-type claims to liberty as the safeguard of either plural goods, or anyway the best means for people to achieve what is best for themselves.

Too great a concern for rationality essentially debars many people from having the power of choice and narrows further the available options from amongst which to choose. Too great a concern with liberty, by contrast, leaves everyone hostage to unwisdom. The trick in political philosophy, and in its practical instantiations such as medical jurisprudence, is to mediate between these competing ideals. To understand this as a practical concern, and in terms relevant to medical law, autonomy demands a focus on assuring that an agent has the rational acumen ('mental capacity') to reach a decision; liberty demands a focus on establishing that she is in the rightful position to reach a decision ('legal capacity').[32]

With regard to autonomy, analysts who take it to mean self-government in an abstract sense tend to look to the purity of agency involved in decision-making.[33] There is a concern not just for the capacity for reason, but also for the effective use of it. If we are value-agnostic, as medical law asks healthcare practitioners to be when it demands that that the content of, or 'rationality' beneath, a patient's decision not be questioned,[34] we judge the quality of a person's exercise of autonomy by the soundness of her reasoning, given her own values.[35] If we know that someone is an avowed socialist and she makes a donation to the Conservative party, we will have reason to presume she is not acting autonomously; that she is mistaken, in some way, about what she is doing. Information, understanding, and the use of reason

[31] Coggon, note 9 above.

[32] Bielby has produced an excellent critique and analysis of this distinction: P. Bielby, "The Conflation of Competence and Capacity in English Medical Law: A Philosophical Critique" (2005) 8 Medicine, Health Care and Philosophy 357.

[33] This claim holds across the most dominant approaches in medical ethics. From the "four principles approach", see e.g. R. Gillon, "Ethics needs principles – four can encompass the rest – and respect for autonomy should be 'first among equals' " (2003) 29 Journal of Medical Ethics, 307, 310; from a Kantian perspective, see e.g. O. O'Neill, note 7 above, pp. 83–4; from a libertarian perspective see e.g. J. Harris, *The Value of Life* (London 1985), p. 196.

[34] *Re T (Adult: Refusal of Treatment)* [1993] Fam. 95; Mental Capacity Act 2005, sections 1(4).

[35] This accords with the principled but *ex ante* "hollow" conceptions of autonomy found, e.g., in G. Dworkin, note 4 above; Frankfurt, note 7 above; Ronald Dworkin, *Life's Dominion: an Argument about Abortion and Euthanasia* (London 1993).

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all contribute to the exercise of autonomy in this sense, even if, as judges of autonomy, we do not exhibit a commitment to any particular overarching rationality. In other words, with a commitment to value agnosticism, we may assess a putatively autonomous decision by reference to a person's own value system; we can assess the coherence of a decision without having to judge the values underpinning it. In this sense, autonomy exists and can be tested in people's exercise of reason, rather than in the substance of their values, reasons, or motives. This does not debar the propriety of questioning fundamental values, or demand a relativist framing. Rather, it founds autonomy on reflective, rational decision-making, with no pre-analytic substantive commitments to the good or the right. Regarding medical law, if we are committed to respecting individual autonomy even when we do not endorse a person's particular values, we will respect a patient's suicidal refusal of a blood transfusion if we know it accords with what she, on reflection, 'really wants'. If we have doubts, however, about the strength of her autonomy, we will not respect the refusal. Doubts may arise because of one of three agency flaws and each of these potentially opens the doors to cynical value-despotism. First, there may be too great an external influence on an individual's autonomy, rendering her coerced and not sufficiently pure in her agency.[36] Second, she may not be sufficiently developed as an agent to come to an autonomous decision on the matter.[37] Finally, we might jettison our value-agnosticism and simply hold that the rationality underpinning a decision is so outrageous or incomprehensible that, although the decision is logically coherent, it *of itself* demonstrates a lack of autonomy.[38]

Crucial to autonomy, therefore, is the exercise of reason, and crucial to rational reasoning is a good ground of knowledge and understanding. It is widely accepted that the maximisation of people's capacity to make autonomous decisions is a good thing. Belief in autonomy allows us to engage with ourselves as moral concepts; we can apply to ourselves concepts such as praise, blame, just desert, and just reward. It allows accountability, with all the goods and all the burdens that carries. Although abnegation or denial of autonomy is sometimes considered desirable,[39] as a rule free will is a good thing to take for granted. It allows individuals to assume responsibility, or have it imposed on them, and for society to develop and maintain institutions based on concepts such as justice. And for most people, it seems to be

[36] *Re T. (Adult: Refusal of Treatment)* [1993] Fam. 95.
[37] *Re E. (a minor)* [1993] 1 F.L.R. 386.
[38] *X N.H.S. Trust* v. *T. (Adult Patient: Refusal of Medical Treatment)* [2005] 1 All E.R. 387. Note we cite the three cases here for illustrative purposes, not with a view to endorsing or criticising the respective judicial decisions.
[39] *Cf* J. Alper, "Genes, Free Will, and Criminal Responsibility," (1998) 46 Social Science and Medicine 1599.

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something that is reasonably taken for granted.[40] For those in whom it would certainly be a fiction, for example, at the extremes, neonates and individuals in a persistent vegetative state, we need to find alternative accounts (if we can) to explain their moral importance. As we move away from such extremes, we find possibilities of 'mixed accounts'; of maximising people's own decision-making, whilst still ensuring some oversight.[41] As a legal principle, autonomy's recognition and the potential for its scrutiny allow judgments of whether an apparent expression of will should be followed. Whilst there are clear reasons not to assure that all decisions are made in accordance with people's second-order desires, where there are potentially serious consequences, an assessment of how autonomous a decision is proves an important regulatory tool. We consider these issues further below, particularly in Part IV.

Turning to liberty, as a political construct, liberty's importance comes in its affording individuals the requisite freedom to act in accordance with their autonomy. To respect the value of autonomous agents, we must permit people to *act* freely, not merely to *reason* freely. Liberty describes the scope of this freedom to act. Liberty is open to legitimate limitation in a way that autonomy is not. People are far from the Kantian abstraction of a person;[42] our 'imperfections' are manifest. To allow a cohesive, functioning society, some external law is required.[43] An author may raise a *presumptive* concern about a measure because it is liberty-limiting, but a failure to respect an autonomous decision does not *conclusively* demonstrate illegitimacy. The value-agnosticism and value-deference that obtain in liberal societies cannot result in out-and-out abdication of claims about good and bad. Although pluralism may allow for contradictory, incommensurable value systems, it does not represent an 'anything goes philosophy' in which no values may be expressed or imposed through law. We may thus work from a presumption that people should be free to act autonomously *provided* they do not breach well grounded external laws that legitimately limit their actions. The grounding of these laws might find itself in one of many conflicting legal or political philosophies. It may

[40] We are not here making substantive claims about determinism; rather, our claim is that law is designed and functions on the basis that free will exists and people live as if it exists. We do not seek, or need, to engage with putative metaphysical proofs relating to freedom of the will for the purposes of this paper.

[41] For a principled approach that seeks to optimise the decision-making power of people with diminished or contested autonomy, whilst also affording adequate protections for welfare, see A. Dimopoulos, *Issues in Human Rights Protection of Intellectually Disabled Persons*, (Farnham 2010).

[42] Eloquently noted in Griffin, *On Human Rights*, note 15 above at 35.

[43] We acknowledge that it can be argued that real respect for autonomy requires a commitment to philosophical anarchism: R. P. Wolff, *In Defense of Anarchism* (Berkeley 1998). We note here that we do not agree with Wolff's arguments, but to engage with questions on the possibility of in-principle legitimacy of the State is beyond the scope of this essay.

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be not causing harm to others;[44] positive obligations derived directly from the receipt of benefits inherent in membership of a stable political system,[45] in being part of a system of civic republicanism,[46] or any of countless other theories. Whatever the overarching normativity, liberty is the freedom within it to act. Liberty marks the bounds of the laws required to mediate the co-existence of people who should be free to act autonomously. At the level of policy, this necessarily allows for situations where people are left free to act in ways that are, at times, not autonomous; by their blanket nature, many policies are bound not to apply perfectly for each individual in each case. It would be unreasonable to expect all and only autonomy-enhancing, liberty-respecting decisions to exist in society. Instead, policies will be geared to optimisation of each. Although theorists disagree on where and why the line is drawn, the key lies in reaching the appropriate pay-off between allowing so much liberty that an excess of harm results, and such restricted liberty that people have too little control of their lives to make them worthwhile.[47]

Both liberty and autonomy are important, but the maximisation of one is not always harmonious with that of the other. Furthermore, mediating between the demands of each is made harder with a commitment to value-pluralism. Respecting pluralism need not represent some form of moral relativism,[48] but can make it hard to judge the quality of a decision. Although we might seek to enhance autonomy, and have good reason to ensure that decisions – especially serious decisions – are reached in accordance with a maximum of autonomy, we must limit autonomous actions that impinge on the deserved liberty of others. That a person has the mental capacity to evaluate a situation and come to some decision of what is right does not automatically entail that she should be at liberty (have the legal capacity) then to act on her decision. As developments in medical law suggest, the need to move away from 'doctor knows best' was unequivocal. However, the purported normative underpinnings of the direction of the move are various. There is general agreement on what was wrong but less agreement on what is right. In the remainder of this paper, we consider how the law protects and improves the exercise of autonomy and the scope of liberty for patients, and show that despite the welcome focus on and concern for autonomy, there are trends in legal developments that are a cause for concern. We first end this section by demonstrating

[44] Mill, *On Liberty*, note 19 above.
[45] C. Wellman, "Liberalism, Samaritanism, and Political Legitimacy" (1996) 25 *Philosophy and Public Affairs* 211.
[46] P. Pettit, *Republicanism – A Theory of Freedom and Government* (Oxford 1997).
[47] In practice there will be "hard cases", such as that of Kerrie Wooltorton, that test this line drawing exercise; see S. McLean, "Live and let die" (2009) 339 British Medical Journal 4112.
[48] Nor need it mean "anything goes": S. Wolf, "Two Levels of Pluralism" (1992) 102 Ethics 785.

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how the distinction between autonomy and liberty allows us to see the different sorts of contention intrinsic to two classes of cases that seem to raise 'autonomy issues'.

First, there are autonomous persons who seek to extend their *liberty*. The leading medical law case in this regard is *Burke* v. *The GMC*.[49] Here there was disconnectedness between autonomy and liberty. Mr Burke's autonomous decision was to receive artificial nutrition and hydration until death; his liberty, as enshrined in law did not guarantee respect for this autonomous choice. By describing Mr Burke, for example, as a 'competent patient', we risk failing to note this distinction. Although he was mentally competent to decide, he did not have legal capacity to decide.[50] It is clearly right that people may have the mental competence to do things that they are not legally entitled to do. To claim otherwise would be to undermine civil and criminal liability for wrongful acts. Consider the case of Dianne Pretty.[51] She had the mental competence to make a decision that she should die but lacked the legal capacity to permit her husband to help her to end her life. Therefore, whilst the case was an affront to Mr Pretty's potential liberty to act in accordance with his autonomy, the law is not necessarily flawed; the legitimacy of his more restrictive liberty is not intrinsically undermined by virtue of its not allowing him all the freedom he (and his wife) desired.

A different manner of concern is raised in cases such as *Chester* v. *Afshar*.[52] Here, the scope of the claimant's liberty was clear; she had a right to receive or refuse the surgical procedure that Mr Afshar had offered. At issue was respect for her autonomy. In order autonomously to exercise her liberty, she argued (successfully) that she ought to have been given more information by her surgeon. In *Chester* the courts were not faced with the task of reappraising the limits of liberty; their role was to assess the proper demands of respect for autonomy.

Having detailed the important conceptual distinctions between autonomy and liberty, and explained how they present themselves in medico-legal cases, we are now in a position to evaluate relevant developments in medical law.

III. The Legal Development of Patient Autonomy

A. Positive Affirmations of Autonomy

Autonomy is partly protected in medical law through the concept of informed consent. Before any treatment is given or procedure

[49] *R (On the Application of Oliver Leslie Burke)* v. *The General Medical Council* [2005] E.W.C.A. Civ 1003.
[50] See the analysis, written prior to *Burke*, in Bielby, note 32 above.
[51] *Pretty* v. *U.K.* (2002) 35 E.H.R.R. 1.
[52] *Chester* v. *Afshar* [2004] 4 All E.R. 587.

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performed on a patient, she must, if competent, give consent. This must be based on the doctor having provided sufficient information about the risks, benefits and alternatives that the patient can weigh up to arrive at an "informed" decision.[53] Surprisingly, it was only in the mid-1980s that the House of Lords first directly considered materiality of risk as a medical law issue. Since then, a series of cases has examined the issue. Their treatment of autonomy has been a process whereby they have taken one step forward, before retreating another two or three, then marching forwards again and not looking back. However, we will show how, in their desire to prioritise autonomy, the courts have supported *liberty* instead, with counterproductive results.

Before considering the case law, the legal issues inherent in informed consent need to be explained. The courts have held that almost all cases involving the inadequate disclosure of information should be dealt with by the law of negligence rather than that relating to trespass; the exceptions are where consent was obtained by fraud or where, due to administrative error, the procedure carried out was different to that consented to.[54] In the vast majority of cases then, the claimant must demonstrate that she was owed a duty of care, which may be assumed in the majority of doctor-patient interactions, and that a breach of that duty has occurred. For information disclosure this means that all "material risks" inherent in the procedure must have been disclosed. Finally, the breach of duty must have caused harm, but this does not mean that had she been informed of the material risk she would not have consented to the procedure.[55]

The most significant case law in this area has focused on the second element, with the question being what constitutes a 'material risk'? The House of Lords first considered this in the landmark case of *Sidaway* v. *Board of Governors of Bethlem Royal Hospital*.[56] Mrs Sidaway was not informed of a 1–2% chance of paralysis inherent in an operation on her back. One of the questions was whether this constituted a material risk. Four of the Law Lords delivered speeches and all agreed that the plaintiff's case must fail, partly because the surgeon had died before the case reached court and there was disagreement over what information had been disclosed. Unfortunately, the legal principle of the case is difficult to fathom because in the four substantive speeches, there are three different definitions of a material risk, ranging from what the reasonable doctor would disclose to what the reasonable patient would expect to be informed of.[57] It is, however,

[53] Section 3(1) Mental Capacity Act 2005.
[54] *Chatterton* v. *Gerson* [1981] 1 All E.R. 257.
[55] *Chester* v. *Afshar* note 52 above. Also Devaney, note 11 above.
[56] *Sidaway* v. *Board of Governors of Bethlem Royal Hospital* [1985] 1 All E.R. 643.
[57] I. Kennedy, "Consent: The Capable Person" in C. Dyer, *Doctors, Patients and the Law* (Oxford 1992).

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clear that each judge, in his own way, held that the law *should* protect, at least to some degree, patient autonomy.[58] We have Lord Sharman's declaration that the issue concerned a patient's "fundamental human rights",[59] Lords Bridge (with whom Lord Keith concurred) and Templeman's compromise that a standard defined by the medical profession should be applied, subject to judicial oversight, and Lord Diplock's view that the onus was on the patient to be kept informed (otherwise the doctor had only to inform of risks that other doctors would think it appropriate to disclose), but that ultimately it was for her to decide what should be done to her own body.[60] The latter may be viewed as paternalistic, yet it is still a recognition of autonomy (and liberty): Lord Diplock stated that "it is my right to decide whether any particular thing is done to my body, and I want to be fully informed of any risks there may be."[61]

In the twenty years after *Sidaway* the courts performed a *volte face* which has been well documented elsewhere.[62] Briefly, the Court of Appeal initially preferred the approach of Lord Diplock,[63] but a series of judgments gradually shifted the definition of material risk towards that of Lords Bridge and Templeman and then on to Lord Scarman's.[64] And in *Chester*, the last House of Lords case on informed consent, the court quoted Dworkin, who emphasises the importance of autonomy, and states that if the law is inconsistent with autonomy then it must be changed;[65] "the right to autonomy and dignity can and ought to be vindicated".[66] Patient autonomy has thus become central to the law in this area. However, the *way* the law has been changed to implement the principle is flawed, as demonstrated by a recent case, which we discuss below.

B. 'Information', 'Understanding' and the Attempt to Implement Autonomy

The courts' rediscovering that autonomy should be at the heart of the law of informed consent is most welcome, but they appear not to

[58] J. Miola, "On the Materiality of Risk: Paper Tigers and Panaceas" (2009) 17 Medical Law Review 76.
[59] *Sidaway*, note 56 above at 649.
[60] *Ibid.* at 659.
[61] *Ibid.*
[62] J. Miola, "On the Materiality of Risk: Paper Tigers and Panaceas", note 58 above, at 80–85 and 95–99.
[63] *Blyth* v. *Bloomsbury* [1993] 4 Med. L.R. 151; *Gold* v. *Haringey Health Authority* [1987] 2 All E.R. 888.
[64] *Smith* v. *Tunbridge Wells Health Authority* [1994] 5 Med L.R. 334; *Pearce* v. *United Bristol Healthcare N.H.S. Trust* [1999] P.I.Q.R. 53; *Wyatt* v. *Curtis* [2003] EWCA Civ 1779; *Chester* v. *Afshar*, note 52 above.
[65] S. Devaney, "Autonomy Rules OK", note 11 above. The work cited is R. Dworkin, *Life's Dominion: an Argument about Abortion and Euthanasia*, (London 1993).
[66] *Chester*, note 52 above, at p. 653, *per* Lord Steyn.

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have fully considered *how* autonomy might be exercised by patients, or indeed what it might mean. The courts' construction of the principle is less than nuanced, perhaps due in part to the limits that courts face in terms of being able only to look at what is presented to them in a given case. Almost all of the relevant cases heard by the courts have concerned patients complaining that they should have received information relating to a specific risk or alternative. The courts have therefore been directed towards considering whether certain information should be classed as 'material' rather than any more substantive or wide-ranging reflections on what autonomy really entails. The end result is a misconceived attempt to prioritise a principle that may at times be counterproductive for patients. The courts' mistake has been to assume that more information provision automatically and necessarily leads to more autonomy in a patient's treatment decisions. Despite modifications to the definition of the materiality of risk, the way in which the courts have imagined the doctor-patient interaction has remained constant; the doctor imparts to the patient a list of risks, which the patient then processes and utilises to form her autonomous decision. This approach has led to the courts confusing autonomy and liberty and prioritising the latter while claiming to champion the former. This protection of liberty, as we demonstrate below, can come at the *expense* of autonomy.

The core problem is that the courts have emphasised the passing of information to the patient while ignoring her *understanding* what she has been told.[67] In this sense, while her liberty to make decisions is protected, her autonomy is not. The prioritisation of the mere disclosure of information can be seen in both *Smith* and *Pearce*, where the judges assumed that provision of information results in autonomy for the patient. In *Smith*, for example, Morland J. (quoting with approval Lord Templeman in *Sidaway*) was clear that a lack of information could lead to a loss of autonomy when he stated that the "patient may make an unbalanced judgment if he is deprived of adequate information".[68] A more explicit synthesis between information provision and the patient's autonomy comes in the case where autonomy was seen as most important, *Chester*, where Lord Hope said:

> *Part of the imbalance between doctor and patient is due to the patient's lack of information*, and, on one view, it is the function of the law to redress the imbalance by providing patients with the "right" to be given that information, or perhaps more accurately imposing a duty on doctors to provide it. … [A] patient with no

[67] A. Maclean, "Autonomy, Consent and Persuasion" (2006) 13 European Journal of Health Law 321.

[68] *Smith*, note 64 above at p. 337.

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> rights is a citizen who is stripped of his or her individuality and autonomy, as well as her clothes, as soon as she walks into the surgery or the hospital.[69]

For his Lordship the 'problem' preventing autonomy was a lack of information on the part of the patient and the solution was to require this information to be transmitted from the doctor to the patient. The decision in *Chester* has thus been hailed as a victory for autonomy.[70] The fundamental flaw is that the provision of information will not, *in itself*, guarantee that an autonomous decision is made. It only guarantees that the information has been passed from the doctor. The courts have consistently combined the language of autonomy with the concept of liberty by insisting that the decision is to be taken by the patient. In *Sidaway*, all the judges emphasised that the decision regarding treatment was for the *patient* to make:

> The existence of *the patient's right to make his own decision*, which may be seen as a basic human right protected by the common law, is the reason why a doctrine embodying a right of the patient to be informed of the risks of surgical treatment has been developed … [and] the courts should not allow medical opinion as to what is best for the patient to override *the patient's right to decide for himself* whether he will submit to the treatment offered him.[71]

Lord Bridge was of the same view, noting that "a conscious adult patient of sound mind is entitled to decide for himself whether or not he will submit to a particular course of treatment proposed by the doctor".[72] Likewise Lord Templeman, who held that "[t]he patient is free to decide whether or not to submit to treatment recommended by the doctor and therefore the doctor impliedly contracts to provide information which is adequate to enable the patient to reach a balanced judgment".[73] Even Lord Diplock emphasised the patient's right to choose, and that "when it comes to warning about risks, the kind of training and experience that a judge will have undergone at the Bar makes it natural for him to say (correctly) it is my right to decide whether any particular thing is done to my body".[74] This approach was abandoned by the Court of Appeal in the bizarre decisions in *Blyth* and *Gold*, but was resurrected subsequently by the courts when they

[69] *Chester*, note 52 above at p. 604, quoting Michael Jones (M. Jones, "Informed Consent and Other Fairy Stories" (1999) 7 Medical Law Review 103 at 129), emphasis added.
[70] E. Jackson, *Medical Law: Text, Cases and Materials*, 2nd edition, (Oxford 2009), 202–3; S. Pattinson, *Medical Law and* Ethics, 2nd edition, (London 2009), at 131. Also, Devaney note 11 above who, nevertheless, acknowledges that the decision does not constitute a panacea.
[71] *Sidaway*, note 56 above at p. 649, *per* Lord Scarman, emphasis added.
[72] *Ibid.* at p. 660.
[73] *Ibid.* at p. 666.
[74] *Ibid.* at p. 659.

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rediscovered the concept of autonomy. Indeed, similar dicta can be found in *Smith*, *Pearce* and of course *Chester*.[75]

Thus the courts have attempted to create autonomous patients by combining a 'list of factors' approach, which they see as serving autonomy, with a demand that the decision is made by the patient rather than the doctor, thereby protecting liberty. There is an assumption that if a doctor lists the risks inherent in a procedure and then allows the patient to make her own choice based on that, her decision is rendered autonomous. This combination of autonomy and liberty may, at first glance, be seen as logically harmonious; an autonomous person without liberty is constricted and any enjoyment of liberty is severely curtailed if choices are not autonomous. Yet the two concepts can combine to cancel each other out, particularly if they are used in an unsophisticated form and without another key to autonomous decision-making; effective communication. While disclosure of relevant information is *part* of serving autonomy, it is not in itself enough. Other factors such as the patient understanding the information must also exist.[76]

The danger in assuming that autonomy will follow liberty is illustrated in the case of *Al Hamwi* v. *Johnston and Another*.[77] The facts are vague, but the essence is that Mrs Al Hamwi was pregnant and wished to undergo an amniocentesis due to a family history of children born with significant physical impairment. She was referred to an antenatal consultant, Miss Kerslake, to discuss the possibility of screening. Mrs Al Hamwi entered the session definitely wanting the screening, but left having changed her mind. She subsequently gave birth to a child suffering from the same impairment as others in her family. At issue was what was said in that private consultation. Miss Kerslake insisted she explained all of the risks, yet Mrs Al Hamwi left under the impression that screening would have a 75% chance of harming the foetus, which is why she changed her mind. Two further points are relevant; first, Mrs Al Hamwi had a very limited command of English, although there was an interpreter present. Second, Miss Kerslake was a Christian who had previously written a book chapter which warned

[75] In *Chester* it was seen to justify a departure from the usual rules of causation, with Lord Steyn declaring that "the right to autonomy and dignity can and ought to be vindicated" (*Chester*, note 52 above, at 693). In *Smith*, Morland J. held that information must be given in a form that "will be understood by the patient so that the patient can make an informed decision as to whether or not to consent to the recommended surgery or treatment" (*Smith*, note 64 above at p. 339). Similarly, in *Pearce*, Lord Woolf held that the purpose of the law was to ensure that patients were not "deprived of the opportunity to make a proper decision as to what course he or she should take in relation to treatment" (*Pearce*, note 64 above, at p. 59).

[76] O. O'Neill, "Ethics for Communication?" (2009) 17 European Journal of Philosophy 167. *Obiter* comments on the importance of understanding have been made: *Smith* v. *Tunbridge Wells*, note 64 above. It is also a core component of the General Medical Council's (GMC) ethical guidance: GMC, *Consent: Patients and Doctors Making Decisions Together* (GMC, 2008), paras [7]–[11].

[77] *Al Hamwi* v. *Johnston and Another* [2005] EWHC 206.

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health professionals that screening was usually a precursor to abortion and "at odds with Christian love".[78] Mrs Al Hamwi suggested at the trial that this might be the reason that the risks had been, in her view, overstated by Miss Kerslake.

It was held that Miss Kerslake had given a balanced warning of the risks and had provided Mrs Al Hamwi with leaflets about screening. The judge speculated that Mrs Al Hamwi had merely misunderstood what she was told and "may have been confused" by the information.[79] Nevertheless, he found for the defendants because it would be unreasonable to demand that doctors ensure that patients understood the information given to them:

> A patient may say she understands although she has not in fact done so … It is common experience that misunderstandings arise despite reasonable steps to avoid them. Clinicians should take reasonable and appropriate steps to satisfy themselves that the patient has understood the information which has been provided; but *the obligation does not extend to ensuring that the patient has understood*.[80]

The judge held that providing leaflets (even to someone who speaks little English) *was* an appropriate method of communication.[81] But Mrs Al Hamwi's decision *cannot* be said to be autonomous if that implies she made an informed decision in accordance with the values that she would live by. Due to her 'misunderstanding', she made the opposite decision. This case is a first instance decision and potentially inconsistent with *dicta* in other cases which refer to understanding as part of informed consent, such as *Smith* and *Chester*.[82] Its importance should thus not be overemphasised, and it may become a legal anomaly. Nevertheless, *Al Hamwi* is important because it is the first case to deal specifically with the issue of communication. Other cases consider whether certain risks or alternatives are 'material', whereas *Al Hamwi* looks at what constitutes adequate disclosure. It therefore has important illustrative value. At first sight the decision seems inconsistent with those in *Smith* and *Chester*, but it may be a strict application of the approach in those cases and how they viewed the problem and its solution. This is because the courts have appeared to suggest that providing information itself will be enough to render a patient's decision autonomous, without anything further. They therefore require only that information is imparted to the patient, rather than

[78] *Ibid.* at para [50].
[79] *Ibid.* at para [74].
[80] *Ibid.* at para [69]. Emphasis added.
[81] *Ibid.* at para [54].
[82] J. Miola, "Autonomy Rued OK?" note 11 above.

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communicated to her.[83] The problem in the application to Mrs Al Hamwi's case is that the information she was given was not understood.

The construction of autonomy in *Al Hamwi*, then, is not at odds with that in *Chester*; the imbalance between doctor and patient was rectified and Mrs Al Hamwi *was* allowed to make her own choice. In this sense, the judge's diagnosis of the problem, and its attendant solution, was constructed in the way demanded, albeit not necessarily envisioned, in *Chester*. But does this expose the law's approach to autonomy as not only flawed but, more seriously, counter-productive for precisely the vulnerable patients who need it most? Its application in *Al Hamwi* suggests this is so. Indeed, Maclean argues that *Al Hamwi* demonstrates the law's increasing insistence on non-directive counselling of patients, leading to the list of risks approach, essentially *abandons* patients to their own decisions.[84] It limits, rather than strengthens, autonomy.[85] Whilst we do not necessarily agree that doctors should do more to persuade patients, we agree that *Al Hamwi* highlights the crucial nature of the patient's understanding what is disclosed. The 'lesson' of *Al Hamwi* is that judges should think further about *how* critical the concepts of understanding and communication are; something the GMC recognises in its latest guidance on consent.[86]

As it stands, the law appears to have shifted from allowing excessive paternalism, past liberalism and into libertarianism, with its attendant notions of self-reliance. The consequences for Mrs Al Hamwi are clear; she lost, or never realised, her autonomy. It is thus right that Maclean refers to *Al Hamwi* as representing the law's "libertarian nadir".[87] The courts have confused autonomy and liberty, ensuring that patients make their own decisions and supporting them in those choices. They have sought to provide them with the tools necessary to reach autonomous decisions, insisting that information be given of the risks inherent in the procedures, but appear not to have taken this protection of autonomy any further.

Although the courts have defined the availability of alternatives as 'material' facts to be disclosed,[88] *Al Hamwi* remains distinct as it relates to the *disclosure itself* rather than *what* is being disclosed. Disclosure means nothing unless the patient *understands* the

[83] *Ibid.*
[84] A. Maclean, note 67 above.
[85] It should be noted however that the courts have, at times, taken a more enlightened approach, such as in *Lybert* v. *Warrington Health Authority* [1996] 7 Med L.R. 71, where the doctor was found negligent for providing critical information *after* the procedure had been performed. Nevertheless, that does not mitigate the decision in *Al Hamwi*, which not only covers a different point but also represents a list of factors approach that is consistent with allegedly autonomy enhancing case law.
[86] GMC, *Consent: Patients and Doctors Making Decisions Together*, note 76 above.
[87] A. Maclean, *Autonomy, Informed Consent and Medical Law* (Cambridge 2009), p. 221.
[88] *Birch* v. *University College London Hospital N.H.S. Foundation Trust* [2008] EWHC 2237.

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information, and it is ironic that protection of liberty *subverted* autonomy. Mrs Al Hamwi needed more than mere information and the law did not provide for that in her case. The judge's approach, demanding the imparting of the list of risks and the patient making her own decision, is, without more, insufficient to protect any meaningful form of autonomy. The law, in this case, fails in its stated aim of protecting patient autonomy. Although we do not want to overstate the importance of *Al Hamwi*, it *is* significant as the first example of a disclosure rather than material risk case and because it represents an extreme application of the approach that can be found in cases such as *Chester*. By promoting liberty, autonomy was forgotten.

C. Negative Affirmations of Autonomy

A libertarian model presumes individuals' decision-making capacity and their ability to look after themselves. However, beyond the cases discussed directly above, English medical law more generally exemplifies something more 'communitarian' than this. It recognises and safeguards the welfare interests of those who are not fully able to protect themselves: freedom to consent applies only to those who are not found to lack the requisite mental capacity. Where an individual is without such capacity, rather than have brutal indifference as a default position, concern for welfare becomes key. Children are protected by law that gives primacy to their best interests,[89] and the same is true for adults who are found to be without capacity.[90] However, a sometimes overlooked point is that this welfare concern under English law applies in a strong sense to everyone. Whilst those with mental capacity are free to make apparently foolish decisions regarding their own health, in order to prove their legal competence they must pass a threshold test. Although it is presumed that an adult patient meets this standard,[91] it is a presumption that is rebuttable on the balance of probabilities.[92] The test for incapacity in section 3(1) of the Mental Capacity Act 2005 raises a strong, albeit negative, affirmation of autonomy:

> [A] person is unable to make a decision for himself if he is unable-
>
> (a) to understand the information relevant to the decision,
> (b) to retain that information,
> (c) to use or weigh that information as part of the process of making the decisions, or
> (d) to communicate his decision (whether by talking, using sign language or any other means).

[89] Section 1 Children Act 1989.
[90] Section 1(5) Mental Capacity Act 2005.
[91] *Ibid.* section 1(2).
[92] *Ibid.* section 2(4).

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This is a negative affirmation of autonomy because the test is used to establish that a patient *lacks* capacity, rather than that she has it. But while the default presumption is positive, it is the doctor's role to assess whether it is the case that the presumption of capacity should be upheld. This raises a duty to ensure that the criteria given in section 3 to sustain the presumption are met; or, to put it both more accurately and more clumsily, without affirming the presumption, a practitioner cannot know that the criteria supporting the default are not not met.

Section 3 places a premium on information, its understanding, retention, and use in deliberation. In the process that led to the passing of the Mental Capacity Act 2005, a functional approach to capacity was the preferred method of assessing capacity. This tests a patient's ability to deliberate, asking whether she has the cognitive skills to consider her decision. The Law Commission's report, which eventually led to the Act, identified that an approach that concentrated on the patient's ability to deliberate was preferable to one that emphasised either her 'status' (as an adult or minor, for example), or the 'content' of her decision.[93] This was the view of the majority of respondents to the consultation,[94] and goes beyond a doctor merely imparting information.[95] It prioritises the patient's ability to absorb the information given to her, assess it, and arrive at a decision. Had Mrs Al-Hamwi, for example, been unable to understand what she had been told, she would have been without capacity. A bald reading of the statutory test for capacity suggests only that a patient need have the *capacity* to understand. But read alongside the developments at common law, particularly *Chester*, a doctor *cannot* simply accept an apparent consent from a patient who has the capacity for understanding, if that consent is based on the patient's having made the decision in ignorance of important factors that would bear on the decision. The combination of common law and statutory duties amount to some level of obligation to ensure understanding. In a given case it *cannot* be acceptable simply to find, less still unquestioningly to presume, that in principle the patient *could* understand, and then dispense facts and presume that they *are* understood.

The role of this crucial component of capacity is, however, widely understated. The law does not simply set up a libertarian paradigm in which each of us can be given information and left to do with it as she sees fit; rather, it recognises the importance of understanding, and the inherent vulnerability that anyone may have in this regard. It is

[93] Law Commission, *Mental Incapacity* (Law Com 231, 1995), para [3.5].
[94] *Ibid.*
[95] Chapter 3 of the Mental Capacity Act's Code of Practice clearly states that the doctor should not only impart the information to the patient, but communicate it in a way that the patient can understand: The Stationery Office, *Mental Capacity Act 2005 – Code of Practice* (London 2007).

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expected that capacity will be assessed by doctors and other health professionals when proposing treatments or examinations,[96] and that for problematic decisions the likelihood of the need for a professional opinion on capacity increases.[97] Whether in the *Al Hamwi* case the health practitioners did all that was reasonable, it is apparent (if not established) from the evidence that the claimant worked from a flawed understanding. If she did not understand and could not reasonably have done so given the limits to her English, the misunderstanding rendered her without capacity. She would have lacked capacity if she were *unable* to understand the information, and it was alleged that she was not given the tools to be able to understand the information as it was presented. In such a situation, better communication would be required and if really she *could not* understand, a best interests assessment should have been made. The law requires either that understanding is likely to be achieved, rather than just that the patient would in principle have the capacity to understand. Otherwise the decision must be made on the patient's behalf. Given the individual values that must feed into an assessment of best interests,[98] it is far from clear that the amniocentesis would not have been the appropriate course of action.

In this regard, the Mental Capacity Act 2005 builds directly on common law doctrine. The statutory test for capacity is not far removed from that established in *Re C*.[99] There is a solid foundation of law that allows practitioners to seek patients' consent in a way that is suitable both in affording liberty to those who ought to have this protected *and* to enhance their autonomy. But if we are right to detect an unhappy trend in the current case law of sacrificing welfare and meaningful autonomy with a misguided protection of liberty, then this is something that can be remedied. In part, this remedy can be found in the concern for patients' understanding of information. Although doctors cannot be obliged to ensure absolutely that their patients understand, a reasonable assessment of their understanding bolsters legal protections of autonomy whilst maximising liberty. Read alone, with indifference to the basis of decision-making and wider legal requirements, the capacity test may only demand that a patient be *capable* of understanding. But read in conjunction with the established medical jurisprudence on consent, there is an obligation to ensure, within the bounds of reasonableness, that there is *actual* understanding.

[96] *Ibid.* para [4.40].
[97] *Ibid.* para [4.42].
[98] Mental Capacity Act 2005, section 4(6).
[99] *Re C (Adult: Refusal of Medical Treatment)* [1994] 1 All E.R. 819. It has been held that the two tests are essentially as one (see *Local Authority X* v. *MM and KM* [2007] EWHC 2003 at para [81]), although this proposition is debatable.

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IV. A Transition to where? from Doctor knows best, to the best being unknowable?

Although the law has developed to allow greater freedoms for patients, ambiguities in the meaning of and justifications for protecting patients' freedoms make the coherence and defensibility of some legal developments questionable. One form of freedom that has been extended over the past two decades is a greater 'negative freedom'; part of what we label "liberty". With regard to liberty, measures and principles have been developed to ensure or enhance patients' freedom from interference by others. This accords with what many understand as Millian liberalism. It recommends denying that doctor knows best, finding instead that each individual is best positioned to direct her own life towards the ends that will produce the best overall position for her. This liberty is only extended to mentally competent individuals: unquestioning deference on the content of welfare, or what serves an individual's interests, evaporates when it is probable that a patient is making a bad decision without possessing the requisite rationality to do so reasonably. Juvenility, mental impairment, and factual ignorance all may bar a person from having privileged liberty at law.

In the legal developments we have considered there is therefore also a focus on a 'positive freedom'; what we label 'autonomy'. Autonomy in this sense is not a freedom to assert a claim right to receive a specific treatment. Rather, it obtains in the function of reason. And here the law has developed on the back of two contradictory bases, reflective of the two starting points for autonomy discussed in Section II. These are rational decision-making given an individual's own values, and rational decision-making given some objective or inprinciple universally acceptable values. The former is the ideal the law seems designed to protect, whilst the latter as employed at law puts a brake on excessive individualism and insufficient regard to the welfare of vulnerable individuals.[100] The changes in legal principle mapped above have been instituted with a paradigm patient in mind who rightfully lives according to her own values. The reinforcements to patient autonomy have thus come as a means of permitting individuals to effect changes in their lives in a manner that is consistent with what *they* would endorse in a second-order manner.[101]

In this way, the trends to enhance patients' liberty and autonomy have emerged on the back of a belief in value-pluralism.[102] Given this belief, or at least a belief that it is not the State's role to rank or order

[100] Coggon, "Varied and Principled Understandings of Autonomy in English Law", note 9 above.
[101] *Cf* G. Dworkin, *The Theory and Practice of Autonomy*, note 4 above; Frankfurt, "Freedom of the Will and the Concept of the Person" note 7 above.
[102] See *In re Z (Local Authority: Duty)* [2005] 1 WLR 959, para 13, *per* Hedley J.

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everyone's values within some framework of (im)permissibility, it has been understood that a doctor, a judge, or any other third party is *not* best placed to decide what treatment a patient should submit to.[103] The patient is treated as most intimately engaged with her own values, beliefs, preferences, and priorities. As these could be drawn from any one of countless and incommensurable rankings, there is no 'right answer' and the patient decides what (if any) treatment is worthwhile. A presumption that doctor knows best is exchanged for one that the patient does; or more accurately that the patient *will* if properly informed. To know best, the patient needs to be sufficiently informed of relevant matters that fall within the health professional's competence. Although she cannot demand a treatment that her doctor thinks inappropriate,[104] she can decide what is best from what is offered, including no intervention whatsoever. In principle, if not perfectly in practice, the doctor deals in facts and the patient in values.

The value pluralism that underpins this position marks it out as an expression of liberalism such as that described by Gray in his book *Isaiah Berlin*.[105] The conception of the patient that it creates is a person who lives in a society governed according to some 'harm principle', but in which otherwise everyone who is mentally competent is free to act in a way that best promotes the good as *she* sees it. It is supported in *dicta* such as Lord Donaldson's in *Re T*, which prize patients' freedom to make decisions for any or no reason, or even irrationally.[106] This support is reinforced by the Mental Capacity Act 2005, but leads to two problems. First is the problem of finding an appropriate means of assessing mental capacity. This is well-trodden ground in academic medical law and ethics. If we allow patients to act according to uninformed or irrational beliefs, how can we use a test based on understanding in order to check that they are acting with sufficient mental capacity? In some cases, the rationality of the decision-making will not be in question but the rationality underpinning the decision will be. For example:

1. The patient believes her blood is evil, and any blood and blood products introduced to her body become evil.
2. The patient believes she is worse off with evil blood inside her.
3. The patient life-threateningly lets her blood, and refuses consent to the introduction of blood and blood products.[107]

[103] *Ms B* v *An NHS Hospital Trust* [2002] 2 All E.R. 449.
[104] *R (On the Application of Oliver Leslie Burke)* v. *The General Medical Council* [2005] EWCA Civ 1003.
[105] J. Gray, *Isaiah Berlin* (Princeton 1997).
[106] *Re T (Adult: Refusal of Treatment)* [1993] Fam. 95.
[107] *The NHS Trust* v. *Ms T* [2004] EWHC 1279 (Fam).

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Here, the rationality of the patient's decision-making is not to be doubted; it is the rationality of her starting point that is questionable. No-one can (dis)prove categorically the truth of her belief, but most, we suggest, would be sceptical about it, and of her likely mental competence given it. Should we honour her wishes? She *can* order *her* values and come to a logical decision. Or do we overrule her expressed will, supposing this to be in her own interests (as the court did in the case on which the example is based)? Such cases test the limits of the value-deference entailed in the pluralism that the law protects. They tease out the difficulty with 'irrationality' as a criterion; although the legal rule would hold that concerns should only be raised by irrationality in the sense of poor exercise of reason, at times there is a pressing concern born of irrationality in the sense of basic reasons for acting.

The second problem comes if the patient is making a decision that seems unremarkable; for example, refusing amniocentesis after being shown information on it. This is troublesome, as we saw in the discussion of *Al Hamwi*, insofar as it gives insufficient cause to interrogate a decision and check it is what a patient 'really wants'. Apparently straightforward decisions will be accepted as part of her right to live according to her own values without excessive interference. The protection of pluralism leads to a pay off. Sometimes patients will have their decisions protected when they are not based on a sufficient understanding and thus do not reflect what they would decide if they were fully informed of all relevant matters relating to the decision. In this situation, far from enhancing autonomy we are paying it lip-service. Is this autonomy backlash inevitable, and how might it be remedied?

We must accept that in a system that does not meddle disproportionately with individuals' freedom to decide what is best for them there will be some 'false positives'. At times people will wrongly be found not to lack decision-making capacity. The possibility of this is heightened if we accept, as English medical law asks us to, that people have strange (peculiar, idiosyncratic, potentially unique) but no less valid value systems; we must *appear* to allow for 'irrationality' in the bases of decisions.[108] To do otherwise would require an account of wisdom that would preclude the potential for a (sufficiently) pluralist outlook. Given this, at times decisions, and thus patients, will be presumed autonomous when they are not so.

This conflict between assuring patients' understanding so that the right outcome is reached, and avoiding indifference towards patients' welfare remains troublesome. Too great a concern for reaching the 'right' decision looks set to reintroduce undue paternalism. Yet a

[108] Mental Capacity Act 2005, section 1(4).

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commitment that in essence says people know what is best, and thus we should just throw information at them and rely on their good sense, also produces a vastly sub-optimal outcome.[109] When studying these questions, it is critical for legal analysts to identify *what sort* of freedom(s) should be enhanced, with a full recognition of the paradigms and concepts that these ideas logically entail, or are entailed within. When a specific defence of autonomy is preferred, attention must be directed at the politico-legal housing that frames it. If we accept the legitimacy of law, we necessarily accept some impingements on liberty and thus on the effectual exercise of individuals' autonomy. Creating a paradigm patient who can rationalise and decide simply because of exposure to information is likely not the right place to begin. But defensible concepts of freedom can be effectuated within the current legal framework. If practitioners and judges pay more attention to the criteria for assessing capacity, the potential autonomy backlash heralded in *Al Hamwi* can be reversed. An acknowledgement of the possibility of some sort of vulnerability in each of us need not give rise to a reversion to unwarranted paternalism. What is widely seen as the law's previous mistake was an assumption that patients could not compute salient information and thus that they were ill-placed to decide.[110] The courts' slow but steady move away from excessive medical paternalism is welcome. What is needed now is vigilance and care to ensure, inasmuch as is reasonable, that patients understand information that would bear on their decisions. Being informed does not simply mean being exposed to information; it means comprehending and computing that information. A presumption that doctor knows best moving to a presumption that the best is unknowable makes assessment of patients' capacity difficult. For autonomy to be worth respecting, however, it is imperative that it be enhanced through the best means possible. We recognise that the appropriate level of scrutiny of a decision depends on context; for example, the potential severity of an outcome may give rise to an especial need to assess autonomy closely. We can not here provide detailed practical advice, but would note that the General Medical Council's guidance on consent provides something approximating the careful, nuanced practical framework that should inform legal as well as professional principles in this area. Doctors must be prepared to exercise their judgment in a responsive manner, respectful of individuals' values whilst not ignoring

[109] M. Flynn, K. Keywood, S. Fovargue, "Warning: Health 'Choices' Can Kill" (2003) 5 Journal of Adult Protection 30.

[110] Whilst there may be dissenters from the view that patients' "empowerment" across the past 30 or so years is a good thing, and we can not *demonstrate* here that the previous, paternalistic regime was based on mistake, there is a wide-spanning and persuasive consensus that champions a system of greater patient autonomy over the previous, much more paternalistic system: canonically, see Ian Kennedy, *Treat Me Right – Essays on Medical Law and Ethics* (Oxford 1988).

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(probable) harms that may befall patients in a way that is incommensurate with the patients' own (probably held) values.[111] Read properly and completely, English medical law on consent does not sit at the 'libertarian nadir' implicit in some judgments; the combination of concern for autonomy and liberty found in the law on capacity, best interests, and informed consent read together permits a much more attractive framework. Key to sound judgments in this area will be a recognition that each of these provides salient matters of concern in an assessment of patients' decision-making.

V. Conclusions

We have highlighted how the courts, when claiming to uphold and prioritise autonomy, have been supporting a form of libertarianism instead. Their conception of autonomy has concentrated too much on *who* makes the decision and that sufficient information is provided. To this end, Maclean's criticism of the law abandoning patients has considerable merit.[112] The law relating to risk disclosure has ignored the importance of understanding, which is perplexing given its critical nature in relation to negative affirmations of autonomy inherent in the Mental Capacity Act 2005's definition of capacity, and the common law test before it.

The ritualistic nature of consent (a patient is given a list of risks and she then makes a decision) has developed for good reason; the courts' desire to prioritise patient autonomy. Nevertheless, with *Al Hamwi* we see an extreme but logical extension of the courts' thinking, and a sign of a misinterpretation of what constitutes 'choice' on the part of patients. For consent, *understanding* must be a precondition, as it *is* in the law relating to capacity. Future courts must recognise this and help patients to make real choices. The application of the law may not be perfect, but by addressing the correct principles it can be improved.

[111] See General Medical Council, *Consent: patients and doctors making decisions together*, London: GMC, 2008. We would likewise note the soundness in this regard of the Mental Capacity Act's Code of Practice, which similarly emphasises the importance of partnership in decision-making, effective communication, and respect for people's own values.

[112] Maclean, note 67 above.

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