

## **Human Rights and Human Experience in Eating Disorders**

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Over the last quarter century, hospital admissions for eating disorders such as anorexia nervosa have continued to rise.<sup>1</sup> During that same period, the law pertaining to food-refusal has generated new challenges. New legal principles have come to prominence in the ongoing effort to introduce robust human rights protections in care settings. And we are seeing a subtle but important shift in the legal framework within which cases of persistent food-refusal are adjudicated. An earlier legal approach could focus narrowly on questions of whether, for example, anorexia nervosa is a mental disorder, whether a particular person living with anorexia presents a ‘danger to self or others,’ and whether involuntary hospital treatment is effective. By contrast, the emerging legal approach explicitly requires attention to the decision-making processes at work in food-refusal, and to the ‘beliefs and values’ that inform a person’s ‘will and preferences’ – both as regards food and as regards treatment. The old questions were hard. The new questions are harder, and they call for new forms of investigation into the phenomenology and psychosocial dynamics of food-refusal.

In what follows, I consider four examples of legal principles that have application in this arena. One example comes from international human rights law; the others derive from a domestic English statute and associated case law. But the issues they raise transcend any one legal jurisdiction. I shall not here propose answers to the questions raised by the application of these principles to food-refusal. Indeed, my principal conclusion shall be that we are not yet equipped to answer them. But if we can bring the questions themselves more clearly into view then we may also be able to develop collaborative, multi-disciplinary research methods suitable for addressing them.



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<sup>1</sup> Data for NHS admissions is published by the NHS Information Centre:  
<http://www.ic.nhs.uk>.

The first legal principle that concerns us is what I will call *the valid refusal principle*. It can be stated as follows: *Refusal-of-treatment is valid only if undertaken by a person with decision-making capacity.*<sup>2</sup> The valid refusal principle is a natural development of one of the most widely recognized principles of medical law and bioethics: the principle of informed consent. On the familiar model, consent to medical treatment is valid (i.e. has legal standing) if and only if three conditions are met: the person is competent (or ‘has capacity’) to consent; the consent is informed; and the consent is voluntary (or ‘un-coerced’).<sup>3</sup> The valid refusal principle extends the first of these three conditions from consent to refusal: a person’s refusal of medical treatment is legally authoritative only if that person is competent to refuse, either at the time when treatment is offered or at the time when an advance refusal is undertaken.

The valid refusal principle has been formulated in a variety of different forms and forums. One particularly striking formulation was provided by Lady Justice Butler-Sloss in a 1997 judgment in the (English) Court of Appeal:

A mentally competent patient has an absolute right to refuse to consent to medical treatment for any reason, rational or irrational, or for no reason at all, even where that decision may lead to his or her own death.<sup>4</sup>

Notice the two edges to the legal sword here. On the one hand Butler-Sloss enunciates an *absolute right* to refuse medical treatment, no matter how dire the consequences. But the scope of that right is explicitly limited: it is enjoyed only *by the mentally competent patient*. Where competence is lacking the absolute right is replaced by duties of care on the part of others. Butler-Sloss’s dictum in re MB interacts with a second finding of roughly the same vintage. In a much-discussed 1994 case, Mr. Justice Thorpe ruled that a patient suffering from paranoid schizophrenia and associated delusions was nonetheless competent to refuse amputation of his

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<sup>2</sup> In what follows I shall use the terms ‘mental capacity,’ ‘decision-making capacity’ and ‘competence’ interchangeably. The term ‘competence’ is more commonly encountered in US legal discourse, while the English legal system speaks rather of ‘mental capacity,’ but the two are effective equivalents in different dialects of legalese, referring to the ability of an individual to make legally significant decisions at the time when they need to be made. See Grisso, T. & Appelbaum, P. (1998) *Assessing Competence to Consent to Treatment: A Guide for Physicians and other Health Professionals*. Oxford: Oxford University Press.

<sup>3</sup> Faden, R. and Beauchamp, T. (1986) *A History and Theory of Informed Consent*. Oxford: Oxford University Press.

<sup>4</sup> *Re MB Court of Appeal*, [1997] EWCA Civ 3093; para. 17(2).

gangrenous foot.<sup>5</sup> This established the key precedent that a finding of serious mental disorder could not of itself warrant a finding of mental incapacity (incompetence).

As formulated, Butler-Sloss's variant on the valid refusal principle goes further than the version I have provided above, and might indeed be accused of hyperbole. For at least under current law, not even a competent adult enjoys an *absolute* right to refuse treatment. For example, in England and Wales, section 3 of the Mental Health Act 1983 (MHA) establishes a legal pathway that can be used to authorise treatment even in the face of a competent refusal. And many jurisdictions operate with statutory provisions for emergency quarantine orders under which a competent refusal can be overridden in the interests of public health. For present purposes, therefore, I shall confine my attention to the more moderate variant of the principle, according to which mental capacity is a *necessary*, but not always *sufficient* condition on the legal validity of a treatment-refusal.

The second legal principle that concerns us here is closely related to the first. In England and Wales, findings such as those of Thorpe and Butler-Sloss ultimately led to the adoption of a new statute: The Mental Capacity Act 2005 (MCA). The MCA provides a legal definition of decision-making capacity and outlaws 'status tests' in which a mental health diagnosis is taken as a sufficient basis for a finding of incapacity. It also establishes a procedure to be used by care-providers and others in making decisions on behalf of those who are found to be incapable of making decisions for themselves. The Act begins by enunciating a set of five principles. The one that concerns us here is what I propose to call *the support principle*: '*A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.*'<sup>6</sup>

The support principle in effect serves as a promise to persons whose decision-making abilities may be impaired. The message is roughly this: before anyone steps in to make a decision *for you*, you shall be provided with the support you need to make that decision *for yourself*. Only if those support measures are either impracticable or ineffective will we then resort to other measures. Variants on the MCA support principle can be found (*inter alia*) in the Mental Capacity Act of Northern Ireland, the Assisted Decision-Making (Capacity) Act of the

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<sup>5</sup> *Re C (An Adult: Refusal of Treatment)* [1994] 2 FCR 151.

<sup>6</sup> MCA, sec. 1(3).

Republic of Ireland, the Natural Persons and Support Measures Bill proposed recently in Bulgaria, the Law for the Promotion of the Personal Autonomy of Persons with Disabilities in Costa Rica, and The Supported Decision-Making Agreement Act in the US state of Texas.



How do these first two principles apply to fraught encounters between those who offer food and those who refuse such offers? What challenges do they generate for those who must apply the principles – or for those to whom they are applied? Some may take the view that their relevance to eating disorders is minimal. In recent history, medical treatment for eating disorders has generally been undertaken in England and Wales either voluntarily (i.e., at least notionally on the basis of informed consent) or else on the basis of a Mental Health Act ‘section,’ invoking the traditional standard of ‘danger to self or others.’ Because involuntary treatment under the Mental Health Act is largely indifferent to questions of decision-making capacity, the legal innovations associated with the Mental Capacity Act are thought by some to be irrelevant.

But this pre-emptive dismissal increasingly rings hollow. In the summer of 2012, the Court of Protection for the first time recorded a finding of mental incapacity as the basis for an involuntary treatment order for anorexia nervosa, including an authorisation for coercive feeding under restraint. Other cases have followed in which the mental capacity construct has been applied to eating disorders. Moreover, the recently adopted Mental Capacity Act in Northern Ireland has adopted a ‘fusion’ approach under which an assessment of decision-making capacity *is* relevant, even in the context of treatment of mental disorders. In England and Wales, NHS procedures now require clinicians to record an assessment of decision-making capacity for all patients being treated for eating disorders, regardless of the legal basis for treatment. So, our first two principles can no longer responsibly be ignored.

Applying these principles to cases of food-refusal, however, presents a host of thorny challenges. Refusal of treatment is common in eating disorders.<sup>7</sup> But under the valid refusal

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<sup>7</sup> Goldner, E., Birmingham, C.L. and Smye, V. (1997) Addressing Treatment Refusal in Anorexia Nervosa: Clinical, Ethical, and Legal Considerations. In Garner, D. and Garfinkel,

principle these cannot be taken at face value; a determination must be made as to whether they reflect decision-making capacity. In order to make such a determination, we need to understand the pathways, deliberative or otherwise, that lead some individuals to refuse offers of food and treatment, even up to the point of grievous ill-health or death. Where decision-making capacity is found to be absent, application of the support principle depends on a determination as to how these individuals can best be helped to recover their decision-making abilities.



In England and Wales, the legal approach to these questions has been decisively shaped by a twenty-five year old ruling in the Court of Appeal. The case concerned a 16-year old girl, known in court papers as ‘W,’ who asked the courts to prevent the local authority from transferring her from a local adolescent in-patient facility to a national eating disorders unit in London. On the matter of decision-making capacity, the judge in the lower court (Thorpe) had written that ‘there is no doubt at all that [W] is a child of sufficient understanding to make an informed decision. I am quite satisfied of that.’ This finding was based both on Thorpe’s own interview with W, and on testimony from an expert witness, Dr G. (an anorexia specialist), who had testified that:

I am convinced that [W] has a good intelligence, and understands what is proposed as treatment. ... She is by no means so severely undernourished that her thinking is physically impaired.

But the Court of Appeal challenged these conclusions. Lord Donaldson wrote for the court:

What with all respect I do not think that Thorpe J took sufficiently into account (perhaps because the point did not emerge as clearly before him as it did before us), is that it is a feature of anorexia nervosa that it is capable of destroying the ability to make an informed choice. It creates a compulsion to refuse treatment or only to accept treatment which is likely to be ineffective.<sup>8</sup>

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P. (eds.), *Handbook of Treatment for Eating Disorders (2nd edition)*. London: Guilford Press, p.450.

<sup>8</sup> *Re W* [1992] 4 All ER 627.

In the end, Donaldson stopped short of ruling that W lacked decision-making capacity for treatment decisions. His final ruling in the case was made instead on the narrow basis of W's status as a minor; in such a context the question of decision-making abilities was not strictly relevant.<sup>9</sup> But his analysis of the question of competence was nonetheless to exercise considerable influence on subsequent law and policy.<sup>10</sup> On Donaldson's schema, refusal of food and treatment is understood as a form of compulsive behaviour; compulsion overwhelms decision-making capacity; the refusal of treatment is therefore legally invalid. Support for decision-making capacity, insofar as it is considered at all, can ultimately only take one form: breaking the force of the compulsion.

There are a number of doubts that might be raised about Donaldson's analysis of W's capacity. First, we should note the difference between Donaldson's *general* observation about anorexia, namely that it is *capable* of destroying decision-making capacity, and any *specific* claim about W's ability to make decisions. We can perhaps all agree that anorexia is *capable* of destroying decision-making capacity. But that by itself is not sufficient to determine whether that potential is realised in the particular instance at hand. After all, anorexia is also capable of causing death, but that does not mean that every occurrence is fatal. There is also scope to doubt Donaldson's claim about the compulsion to refuse (effective) treatment, particularly in light of Donaldson's description of W as having previously consented to treatment at the local adolescent facility (including consent to feeding by nasogastric tube) and his report that treatment on that basis had successfully stabilised her weight in the period prior to court proceedings.

But my purpose here is not to quibble with Donaldson's reasoning, nor to challenge his conclusion. There is a much broader lesson to be drawn. To bring it into view, we need first to appreciate the extent to which Donaldson's application of the valid refusal principle is *predicated on a claim that specifically concerns the psychosocial dynamics of food-refusal*. W's refusal of food and of treatment is an intrinsically social act, undertaken in response to an

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<sup>9</sup> Because W was only 16, the court found she lacked the authority to refuse a treatment that had been found by someone with parental authority to be in her best interests, objectively understood.

<sup>10</sup> See for example: 'Mental Incapacity' *Law Commission* No 231 (1995), para. 3.17; *Mental Capacity Act 2005: Code of Practice*. London: Department of Constitutional Affairs, 2009, para 4.21-22.

offer and witnessed by others. On Donaldson's interpretation, those refusals were the product of a compulsive psychological force that precludes the exercise of genuine decision-making.

But the text of Donaldson's judgement can also be used to sketch an alternative picture of the psychosocial dynamics at work in W's refusals. On this view, what W seeks above all is some modicum of control over her chaotic life. W spent her childhood buffeted from one foster placement to another, suffering a string of tragic personal losses and being victimised by bullying and abandonment. The behaviour that others experienced as health-undermining food-refusal was for her a strategy for asserting and maintaining a limited domain of self-determination in her affairs. Refusing the transfer to the London specialist facility was another such strategy. As she explained to the court, W sought to maintain the relationships (strained though they may have been) both with staff and with other patients at the local adolescent facility, and with one nurse in particular who had assisted in her treatment. Once we start to think along these lines in tracking the psychosocial dynamics of W's refusals, it seems far less clear that she lacks decision-making capacity. On the contrary, it begins to look as if W's high-risk refusals were in fact the product of a fraught deliberation under considerable pressure about how to achieve a goal that mattered a great deal to her. Might W's refusals actually have been a consummate expression of decision-making rationality?

My aim is not to recommend one of these two interpretations of W over the other. The crucial point here is that we have two opposed interpretations of the psychosocial dynamics at work in W's refusals – and of course other interpretations may be possible. In order to apply the valid refusal principle and the support principle, we either need an evidenced ground for choosing among these interpretations or we need to develop a perspective from which they can somehow be combined in a single view. Are W's reasons for resisting the transfer best understood as mere rationalisations developed to justify her compulsive refusals? Or could her compulsive refusal itself be the product of her decision-making processes? In the absence of resources for addressing these questions we seem to reach a legal impasse: we can't determine whether W's refusals satisfy the standard of legal validity and we are poorly equipped to keep faith with the promise of support.



The third principle that concerns us is what I shall refer to as *the Aintree principle*, in reference to the case in which it was first enunciated.<sup>11</sup> The Aintree principle applies in situations where a person is found to lack decision-making capacity, and a decision must therefore be taken by someone else. In England and Wales, the decision in such circumstances is governed by the so-called ‘best-interests standard.’<sup>12</sup> The decision-maker (in the limiting case, the courts) must have regard to a variety of factors in reaching an overall judgement as to the individual’s best interests in the matter. Among the factors that are to be taken into account are the person’s ‘wishes and feelings, ... beliefs and values.’<sup>13</sup>

In *Aintree*, the UK Supreme Court reversed a judgment of the Court of Appeals on the grounds that the best-interests standard had been incorrectly applied in the case of David James, a 68-year old patient suffering serious physical ailments that ultimately resulted in loss-of-consciousness. Writing for the Supreme Court, Lady Justice Hale chided the judges of the Court of Appeals for having applied what in law is known as a ‘reasonable man test,’ rather than considering the wishes, feelings, beliefs and values of Mr James himself:

Finally, insofar as Sir Alan Ward and Arden LJ were suggesting that the test of the patient’s wishes and feelings was an objective one, what the reasonable patient would think, again I respectfully disagree. ... [I]nsofar as it is possible to ascertain the patient’s wishes and feelings, his beliefs and values or the things which were important to him, it is those which should be taken into account because they are a component in making the choice which is right for him as an individual human being.<sup>14</sup>

We can accordingly summarise the Aintree principle as follows: *In assessing the best interests of a person lacking capacity, the assessor must take into account the person's values, whether or not those values coincide with those of ‘a reasonable patient.’*

The final principle with which I shall be concerned is perhaps best cast in the form of an imperative: *Respect the rights, will and preferences of persons living with disabilities! **The rights, will and preferences imperative*** derives from the provisions of the United Nations

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<sup>11</sup> *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67.

<sup>12</sup> MCA, sec. 4.

<sup>13</sup> MCA, sec. 4(6)(a-b).

<sup>14</sup> *Aintree*, para. 45.



Convention on the Rights of Persons with Disabilities (CRPD). The CRPD is a landmark human rights instrument, adopted by the UN General Assembly in 2006 and more widely ratified than any other international human rights convention. The Convention operates with a ‘social model’ (rather than a ‘medical model’) of disability. Its scope extends beyond the traditionally recognised physical and sensory disabilities, encompassing a wide range of conditions that have the potential to hinder a person’s ‘full and effective participation in society on an equal basis with others.’<sup>15</sup> This would certainly include many individuals who are living with eating disorders. CRPD Art. 12 requires states to adopt ‘appropriate and effective safeguards to prevent abuse in accordance with international human rights law.’ Such safeguards must take a proportional approach in ensuring, *inter alia*, ‘respect for the rights, will and preferences of the person.’<sup>16</sup>

The complexities raised by our third and fourth principles are considerable; I shall not seek to do justice to them here. But an immediate corollary of each is worth noting. When applying the best-interests standard to the refusing of food, the Aintree principle requires that regard be given to the *values* that inform the refusal – taking care not to presuppose that these coincide with the values that motivated the offer. The fourth principle mandates respect for the will and preferences at work in such refusals. But all this begs a prior set of questions. What exactly are the values at work in food-refusal? What are the will and preferences of a patient who risks her life and health with persistent refusals of food and treatment? A good faith effort to adhere to these legal principles requires that we grapple with these difficult questions.

In considering the values and preferences at work in food-refusal, it is common to cite such things as avoidance of weight-gain, low BMI, or ‘thinness at any cost.’ Patients themselves sometimes explain their values and preferences in these terms,<sup>17</sup> and we hear similar accounts from family members, frontline care-providers and judges. But is this an adequate characterisation of the values and preferences at work? One reason to doubt its adequacy pertains to a distinctive form of ambivalence that is commonly reported in this patient

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<sup>15</sup> CRPD, Preamble.

<sup>16</sup> CRPD, Art 12(4).

<sup>17</sup> Tan, J., Hope, T., Stewart, A. & Fitzpatrick, R., Competence to Make Treatment Decisions in Anorexia Nervosa: Thinking Processes and Values. *Philosophy, Psychiatry, and Psychology*, 13(4), 267-282.

population.<sup>18</sup> If food-refusal is characterised by ambivalence then multiple and conflicting values would seem to be in play. So how should this ambivalence be understood and how should its broader normative context be characterised? Where thinness is an operative value, is it valued as an end in its own right, or is it better understood as a potentially costly means to some highly valued further end? If so, what are those further ends? Control? Autonomy? Recognition? Retaliation?



What should we conclude from this selective legal survey? We have seen that new statutes, new case law and new human rights obligations are raising challenging questions about the refusal of food and treatment in the context of eating disorders. The traditional legal approach had focused primarily on questions of prognosis: does the patient pose a risk to herself? What is the likelihood that coercive treatment will be effective? The new legal approach forces us to address questions of quite a different order – about the decision-making processes of persons who systematically refuse food, about the values and preferences reflected in such refusals, and about the forms of support that can be provided to help people affected by eating disorders make their own decisions wherever possible.

We will not be able to address these questions, much less answer them, if we confine our attention to a medical or behavioural description of the phenomena or to statistical studies of risk factors and co-morbidity. By their nature, these new questions are of an order that can only be addressed by investigating the *experiences* of persons who engage in the systematic refusal of food, and by studying the *psychosocial dynamics* at work in the often-intricate interplay between the act of offering food and the act of refusing the offer. Moreover, we need to struggle with what philosophers call questions of *moral psychology*, and consider how to bring evidence to bear in distinguishing between genuine deliberation and compulsion-masking rationalisations.

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<sup>18</sup> Williams, S. & Reid, M. (2010) Understanding the Experience of Ambivalence in Anorexia Nervosa: the Maintainer's Perspective. *Psychology and Health*, 25(5), 551- 567.

Some may conclude that these questions are too murky, and the associated research methods insufficiently rigorous to yield legally attestable evidence. Some skeptics may prefer to return to the old medical-model questions about prognosis. But it is far from clear that it is possible to turn back the legal clock. The alternative is to develop a richly multidisciplinary research approach to probe these issues seriously. This will require a collaboration not only among jurists, psychological therapists, nutritionists, sociologists, phenomenologists and ethicists, but most importantly with those who have first-hand lived experience of food-refusal, and with the psychosocial dynamics associated with it.<sup>19</sup>

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