To treat or not to treat: legal and ethical issues in the compulsory treatment of anorexia

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ABSTRACT

Treatment resistance is a characteristic feature of anorexia nervosa, and is usually regarded as a symptom of the illness. In the case of some chronic anorexics, however, rejection of therapeutic intervention may be the result of reasoned decision making. Some patients ('endstage' anorexics) may feel their quality of life so poor and the prospects of recovery so slight that they would prefer to be allowed to die. For others ('identity' anorexics), their illness may have become so integrated into their sense of self that they reject attempts to 'cure' them, despite being aware of the risks this poses to their health. Under New Zealand law, there is the possibility that such patients could be considered legally competent under the Protection of Personal and Property Rights Act (PPPRA), but mentally disordered under the Mental Health (Compulsory Assessment and Treatment) Act (MHA). Whether compulsory treatment is lawful would thus depend on the piece of legislation used when assessing the need for a treatment order. A principlist analysis of the ethics of compulsion suggests that enforced treatment is justified in the case of identity anorexia (providing effective treatment is available), but not in end-stage anorexia. I conclude that current legislation needs to be amended to ensure that the PPPRA and the MHA can be applied to anorexic patients in a legally consistent and ethically appropriate manner.

This dissertation is dedicated to all those who have known the unbearable being of lightness.

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CHAPTER ONE: INTRODUCTION

Anorexia nervosa is a baffling and frightening condition whereby sufferers (typically bright young women)¹ deliberately starve themselves to the point of severe and life-threatening emaciation.² Despite years of research into the genetic and biological origins of the illness, the physiological aetiology of anorexia remains elusive. Similarly, numerous theories have been advanced to explain the role of social and cultural factors that motivate the anorexic to value the pursuit of thinness above all else. Anorexia also remains singularly intractable to treatment, primarily because of the ambivalence, or outright resistance of patients, and the use of coercion in therapy is controversial. Although there has been a great deal of academic discussion of these issues, no purely intellectual approach can adequately capture the subjective reality of living with the condition. For clinicians, anorexia is a product not of free choice but of biological and social forces outside the sufferer's control: an illness to be cured. For some anorexics, particularly those who have been ill for many years, however, anorexia becomes indistinguishable from identity.³ This raises important questions about whether anorexics ought to be subject to compulsory treatment on the basis that treatment refusal is merely a symptom of the illness itself, or whether some anorexics might retain the ability to abjure therapy, not because they fear weight gain, but because they value their thinness more than they fear the risks associated with starvation. Difficulties in measuring the efficacy of different treatment approaches, and a belief that coercion is anti-therapeutic⁵ further undermine support for the use of compulsion on anorexic patients. As a result, a number of commentators have called for legal intervention to be used sparingly, applied to only critically ill patients whose physical state impairs their ability to make competent treatment decisions, and (if mental health legislation is invoked),

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¹ Bulik CM. *et al.* 'Anorexia nervosa: definition, epidemiology, and cycle of risk.' *Int. J. Eat. Disord.* 2005; 37:S2-9; Hoek HW. Incidence, prevalence and mortality of anorexia nervosa and other eating disorders. *Curr. Opin. Psychiatry.* 2006; 19(4):389-394.

² Although anorexia affects both men and women, the majority of patients are female. For the sake of simplicity, I will use the female pronoun throughout.

³ These contrasting positions are more fully addressed in chapter two.

⁴ Bulik CM. *et al.* 'Anorexia Nervosa treatment: A Systematic Review of Randomised Controlled Trials.' *Int. J. Eat. Disord.* 2007; 40:310-320.

⁵ It may, for example, convince the patient recovery is impossible (as it did in my case), entrench mistrust of clinicians, or encourage the development of more difficult to treat behaviours such as binging and purging. Dresser R. 'Feeding the Hunger Artists: Legal issues in treating anorexia nervosa.' *Wis. L. Review* 1984:297-374 at 319.

to be accompanied by an independent assessment of competence and/or best interests using guardianship legislation.⁶

In New Zealand, either the Protection of Personal and Property Rights Act 1988 (PPPRA) or the Mental Health (Compulsory Assessment and Treatment) Act 1992 (MHA) can been used to authorise involuntary hospitalisation and treatment of anorexic patients. The PPPRA permits the use of compulsion for patients who are incompetent to make the relevant medical decisions while the MHA authorises involuntary treatment of people suffering from a 'mental disorder' as defined by the Act. In addition, as many anorexic patients are adolescent, parents or guardians are often in the position to make decisions on their child's behalf. Adult anorexics, however, particularly those who have been ill for many years, pose a unique problem because they may retain (or regain) legal competence to refuse treatment, while still being regarded as mentally disordered under the MHA.

This thesis examines the legal and ethical issues surrounding the use of compulsion on two categories of treatment-resistant adult chronic anorexic:

- 1. 'End-stage' anorexics: that is, patients who refuse life-sustaining treatment because they consider their current quality of life so poor and the prospect for recovery so slight that they want to be allowed to die.
- 2. 'Identity' anorexics: those who appear to have integrated anorexia into their sense of self, or regard anorexia as a meaningful way of life with benefits they value highly. Although acknowledging their illness and the dangers associated with it, they reject treatment in preference to remaining as they are.

My analysis addresses three key questions. Firstly, how does the law currently apply to such patients? Secondly, is the use of coercion ethically justified in either or both cases? And, thirdly, based on this ethical analysis, how *ought* the law to deal with end-stage and identity anorexia? In answering these questions, I attempt to combine my own experience as an anorexic with a critical analysis of the legal and ethical issues, and suggest ways in

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⁶ Ibid; Lewis P. 'Feeding anorexic patients who refuse food.' *Medical Law Review* 1999; 7:21-37; Carney T. 'Anorexia: A role for Law in Therapy?' *Psych. Psychol. Law* 2009; 16(1):41-59.

which New Zealand law could be amended to ensure that compulsory treatment for anorexic patients is both legally and ethically appropriate.

1.1 How does current law handle end-stage and identity anorexia?

Both the PPPRA and the MHA provide statutory justification for involuntary treatment, but the criteria for intervention differ.⁷ Both pieces of legislation also raise important conceptual and ethical questions about when the use of compulsion is justified (see chapter three).

The PPPRA, with its focus on competency and the right to self-determination, is thought to better protect patients from paternalistic and potentially inappropriate clinical intervention. Its use avoids the stigma associated with 'mental illness', and it is more empowering and inclusive of patients and their families. Assessment begins from a presumption of competence, and compulsory treatment can be authorized only if a person lacks, wholly or partly, the ability to make or communicate competent decisions *and* intervention is necessary to ensure that person's rights and welfare are protected. The criteria for assessing competence in decision-making are largely procedural, depending on a person's ability to understand and believe information relevant to the question at hand, and to balance that information to reach a settled choice. Both end-stage and identity anorexics could potentially be regarded as competent to refuse treatment under the PPPRA.

In the case of end-stage anorexia, the likelihood of treatment succeeding is extremely low. The decision of such a patient to refuse life-sustaining intervention because she considers her quality of life (and prospects of improvement) unbearable could be regarded as analogous to a patient with aggressive and treatment-resistant cancer rejecting treatment in favour of spending their final days free of the side effects of chemo- or radiotherapy.⁸

In the case of identity anorexia, although not a matter of life and death (at least in the short term), most people would think that her treatment resistance is a symptom of the illness. An apparently irrational decision can still be legally competent, however. Decisions regarding

⁸ Even if the patient were judged incompetent, treatment futility would be grounds for rejecting an application for a treatment order.

⁷ For a discussion of the comparative advantages and disadvantages of using mental health and adult guardianship legislation to manage anorexic patients see Carney T. *et al.* 'Institutional options in management of coercion in anorexia treatment: The antipodean experiment?' *Int. J. Law Psychiatry* 2003; 26:647-675.

treatment require more than just a balancing of the physical costs and benefits, and she could legitimately decide that she considers that the benefits she gains by way of security and self esteem from her illness outweigh the physical and emotional costs of 'recovery.' Providing she can demonstrate a clear understanding of her condition, the risks it poses, and a willingness to accept periods of hospitalisation if her physical condition becomes severely compromised, her decision to reject medical or psychological intervention could potentially be considered competent. Indeed, at least one study has found that many anorexics meet the requirements for legal tests of competence. The structure of the PPPRA and its application to anorexic patients is therefore the focus of chapter four.

The critical determination under the MHA is not whether a person is competent, but whether she is suffering from a mental disorder characterised by delusions, or a disturbance of mood or perception or volition or cognition that severely diminishes her capacity for self-care, or places herself or others at serious risk. The five characteristics that constitute an 'abnormal state of mind' are defined in lay rather that psychiatric terms, and have recently been found to include the sort of 'pathological' values characteristic of severe personality disorder, as well as more commonly recognised mental disorders. Danger to self and/or others is assessed longitudinally, and the inclusion of intermittent as well as continuously abnormal states of mind means that patients can continue to be compulsorily treated even when their acute symptoms abate. Many anorexics fit the definition of a mentally disordered person under the MHA, ¹⁰ and the criteria of sufficiently flexibility that both end-stage and identity anorexics could be compulsorily treated under the Act, regardless of their competence and, potentially, despite such treatment being futile. 11 In chapter five, the MHA will be described, with particular focus on anorexia as a disorder of volition and/or cognition, to show how these criteria are flexible enough to accommodate an anorexic identity as a mental disorder. It will also highlight the particular difficulty that arises with respect to release of patients on the grounds of treatment futility.

⁹ Tan JOA. *et al.* 'Competence to refuse treatment in anorexia nervosa.' *Int. J. Law Psych.* 2003; 26:697-707.

Symptoms such as a distorted self-image, depression, phobic fears of food and weight, and the persistence of behaviours that put them in physical danger despite professing no wish to die, have been variously described as disorders of perception, mood, volition and cognition.

Although the court must also be satisfied intervention is necessary before a treatment order is granted, there is no 'necessity' test when a patient applies to the Tribunal or courts on a subsequent application for release.

1.2 Is the use of compulsion in end-stage or identity anorexia ethical?

The discrepancy between the PPPRA and the MHA in regard to whether the use of compulsion in end-stage and identity anorexia is lawful is unsatisfactory, ¹² and one or both pieces of legislation ought to be amended so that the two acts are aligned. One way of determining how this could be achieved is to consider when the use of compulsion is ethically justified. Western biomedical ethics in founded on respect for the principles of autonomy, non-maleficence, beneficence and justice. ¹³ Because the question of whether the use of compulsion is appropriate when dealing with anorexic patients is a medical as well as a legal issue, a principlist approach can be used to assess whether the way the MHA and the PPPRA are being applied in an ethical manner. Such analysis can also suggest ways in which the law could be changed to ensure that that both Acts are ethically sound, and legally consistent.

Determining whether constraining another person's actions is ethically justified depends upon the balance between the principles of non-maleficence, beneficence, and autonomy that apply in any particular situation. ¹⁴ In medicine, beneficence and non-maleficence (the requirements on doctors to act in the best interests of their patients) are the oldest of the four principles, but current medical (and legal) practice gives great normative value to autonomy. We generally consider an individual is in the best position to judge his or her own best interests, and believe it is wrong to interfere even if we think they are making a mistake. Thus, in medicine, we consider freedom of choice necessary for (or more important than) ensuring an individual's physical welfare, and that a patient ought to determine where her best interests lie unless we have reason to believe her autonomy is compromised (and intervention is necessary). If she is not able to make autonomous decisions, the potential benefits of intervention must also outweigh any possible harm. This leads us to the following conclusion with respect to treatment resistant anorexics:

Compulsory treatment of an anorexic patient is ethically justified if and only if:

1. She is treatment resistant.

¹² Although this thesis concentrates on anorexia, it is also relevant to other illnesses such as clinical depression (where a patient may refuse treatment because they do not consider themselves worth the time, attention and expense involved), or to personality disorders (characterised by overvalued ideas rather than disordered thinking processes).

¹³ Beauchamp TL. & Childress JF. <u>Principles of Biomedical Ethics</u> (Fourth edition). New York: Oxford University Press, 1994.

¹⁴ Just access to scarce resources is also an important principle, but is more relevant in terms of social rather than individual medicine with regard to the current discussion.

- 2. Her health and welfare are seriously endangered.
- 3. Potentially effective treatment is available (and would not be undermined by the use of compulsion).
- 4. The ability to make relevant decisions in an autonomous manner is compromised by her illness.

In the case of an end-stage anorexic (for whom treatment is futile), condition three cannot be satisfied, regardless of the patient's competence. Treating the life threatening aspects of anorexia will "save the patient's life", but force her to exist under conditions in which she would rather be dead. Although there is a very strong desire to override the patient's objections in the hope that recovery *might* be possible, forced intervention is certain to cause her considerable suffering, with no guarantee she will derive any benefit other than an extension of a life she finds intolerable. The principle of non-maleficence imposes an obligation not to carry out actions that are likely do more harm than good, and thus involuntary treatment in this situation is morally wrong. Because competence is not assessed under the MHA, and treatment futility is not taken into account when a patient under indefinite commitment applies for release, end-stage anorexics ought not to be treated under this legislation until these problems are resolved.

In the case of identity anorexia, the critical question is whether the patient is acting autonomously in rejecting treatment.¹⁵ Although she may understand the risks and benefits of accepting or rejecting treatment at an intellectual level, anorexic identity arises from the lived experience of the illness, and constrains the anorexic's ability to imagine living in any other way. Because an identity anorexic fails condition four, compulsory treatment can be justified if appropriate treatment is available.¹⁶

The ethical justification for overriding her refusal of treatment is further strengthened by the fact that taking the opposite approach – supporting treatment refusal by to the self-chosen (or treatment resistant) anorexic – may further limit her autonomy by making it more

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¹⁵ Taking a long-term perspective on the serious effects of starvation or semi-starvation on her health and welfare.

¹⁶ In addition, if we consider identity develops through interaction with others, anorexia represents a disruption of the normal process by which we develop as relational beings, and the identity anorexic is thus unable to meet her social and emotional needs in the way most humans can. Because such factors weaken an anorexic's autonomy, other factors (such as concern for her welfare, her family, and wider social implications of accepting anorexia as a 'valid' lifestyle) assume greater normative importance.

difficult for her to change, and by lessening her ability to choose to accept treatment at some future time.

Although such a patient could potentially be regarded as competent under the PPPRA, this is not a conclusion that many people would find satisfactory. The most instinctive reason most of us would give for feeling uncomfortable with the idea that an identity anorexic could legitimately choose to reject treatment is not merely because her choice appears irrational, but also that we think her ability to make a free choice is in some important sense impaired by, or as a consequence of, her illness. Because mental competency is considered a prerequisite for autonomous action, tests of competence or capacity are used as a way to assess the ability of an individual to make autonomous choices. The fact that in the case of identity anorexics, our legal definition of competence does not seem to adequately reflect our understanding of autonomy raises important questions regarding the adequacy of current competency criteria, and suggests these criteria should be broadened.

1.3 How ought the law to handle end-stage and identity anorexia?

As things currently stand, my conclusion will therefore be that the PPPRA is preferable to the MHA for determining whether an end-stage anorexic should be compelled to accept life-sustaining treatment, while the flexibility of the MHA makes this the preferable legislation when dealing with identity anorexics. In the final chapter I examine several options for resolving this situation. I propose defining 'understanding' in the PPPRA to ensure the competency test specifically considers the ability of proposed patients to fully appreciate the benefits and risks of treatment both intellectually and as applied to *themselves*. The modified competency test could then be included in the MHA as well, along with the requirement for treatment necessity to be considered whenever a treatment order is reviewed. This would ensure that both identity and end-stage anorexics were treated ethically and equitably under both pieces of legislation.

CHAPTER TWO: ANOREXIA NERVOSA

The refusal of food has a long tradition both as a form of protest and an ascetic discipline. Unlike those engaged in politically motivated hunger strikes or religious fasts, however, anorexics are motivated by an intense fear of being fat and attach an inordinate value to thinness and the values associated with it, sometimes to the extent that they would rather die than gain weight. Anorexia is a 'self-imposed' illness in the sense that anorexics persist in and defend their behaviour in the face of efforts to persuade them to gain weight. It may also become a way of life that the anorexic is unable to change, an inescapable cycle that drags sufferers into a life of loneliness and misery. Suicide is the major cause of death for those with the condition. Both the medical profession and the general public regard anorexia nervosa as a mental illness, and treatment consists of a range of interventions to encourage weight gain and help the patient resolve the psychological issues that underlie the disease.

An alternative approach, advocated by some anorexics and therapists, describes anorexia not as an illness, however, but as a meaningful subjective experience that may become integrated into personal identity. Although some people experience anorexia nervosa as a transitory, adolescent episode, it is estimated that less that half of those with anorexia fully recover, and up to 20% remain chronically ill, and may come to regard their illness as an essential part of who they are. Understanding anorexic behaviour as purposeful, or as an aspect of personal identity, is therefore important when it comes to answering the question: 'should we force treatment on anorexics?'

2.1 Anorexia nervosa as a medical condition

Anorexia nervosa is a serious and life-threatening illness that affects about 5% of New Zealand women of 15-45 years old, with another 3-5% with a sub-clinical form. There are an estimated 1300 diagnosed anorexics in the country, of which up to 10% will be male. ¹⁹ Sufferers utilise starvation, exercise, laxatives, and purging in various combinations to attain pathologically low weight (BMI<18). Although the core psychopathology of anorexia

¹⁷ It is accepted by many therapists that anorexia may be an adaptive behaviour that enables the patient to deal with stresses and conflicts, albeit one that becomes an overwhelming obsession that reinforces the original problems.

Pompili M. et al. 'Suicide in anorexia nervosa: a meta-analysis.' Int. J. Eat. Disord. 2004; 36(1):99-103.

¹⁹ http://www.eatingdisorders.org.nz.

nervosa is not clearly understood, most people regard it as a mental illness defined by a combination of physical and psychological symptoms. The Diagnostic and Statistical Manual of Mental Disorders, Volume (DSM-IV-TR)²⁰ list the following criteria which must be met before for diagnosis of anorexia nervosa is given:

- Refusal to maintain body weight at or above 85% of the minimal normal for the person's age and height.
- Intense fear of gaining weight or becoming fat.
- Disturbance in the way in which body weight or shape is experienced, undue influence of body-weight or shape on self-evaluation, or denial or seriousness of current low weight.
- Absence of at least 3 consecutive menstrual cycles (amenorrhoea), or delayed/arrested onset of puberty.

In addition, other medical and psychological causes must be ruled out. The World Health Organisation's International Statistical Classification of Diseases and Related Health Problems (ICD-10) also specifically mentions that the weight loss must be self-induced by either caloric restriction, and at least one of the following: excessive exercise, self-induced vomiting or purging, or the use of appetite suppressants and/or diuretics.

A number of secondary symptoms resulting from inadequate nutrition may be severe and life threatening. Serious consequences of anorexia include osteoporosis and infertility,²¹ damage to organs such as the heart, kidney and pancreas, epileptic attacks and cardiac arrhythmia/arrest due to electrolyte imbalances, hypoglycaemia, and suppressed immune function. Most (but not all) of these symptoms resolve as nutritional status and weight are restored.²² Starvation also impairs cognitive ability, and weight gain (at least in severely emaciated patients) is a necessity for meaningful psychological treatment. As a result, the first line treatment usually focuses on weight restoration as both a medical necessity and prerequisite for other forms of therapy.

As mentioned above, the primary symptom of anorexia is the deliberate maintenance of a pathologically low body weight through food restriction and/or compensatory

²¹ Usdan LS. et al. 'The endocrineopathies of anorexia nervosa.' Endocrine Practice 2008; 14:1055-1063.

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²⁰ American Psychiatric Association (1994), United States of America.

The obsessive rumination about food, narcissism, infantile regression, and many of the neurological and endocrine abnormalities are identical to those found in other staving people and are corrected by restoring body weight to a critical level (90-95 pounds). Other characteristics, such as the *way* in which hunger is experienced, the denial of physical weakness and the pride in the weight loss are unique to anorexia. Bruch H, The Golden Cage. Cambridge, Mass: Harvard University Press, 1978; p6-8, 19-20, 196.

behaviours. Although improved nutrition will resolve some of the physiological *sequelae* of starvation (for example lack of concentration or muddled thinking processes) weight restoration, in and of itself, will not address all the psychological or physiological factors underlying the disorder.²³ Treatment involves a combination of re-feeding, nutritional counselling, long-term psychological therapy and sometimes medication.²⁴ Although there is disagreement about the need for enforced weight gain once a patient is out of immediate physical danger, addressing anorexic behaviours and/or underlying psychological factors will (eventually) lead to increased weight even in the absence of a deliberate re-feeding programme.²⁵ Given the central importance of weight in an anorexic's worldview, resistance (or ambivalence) to treatment is common. Voluntary participation in treatment (both inpatient and outpatient) is thought to be more effective and ethically acceptable because the use of coercion erodes the anorexic's already fragile autonomy, thus increasing her anger, isolation, and determination to persist in her behaviours.²⁶ On the other hand, there is evidence that patients subjected to involuntary treatment later acknowledge it as both necessary and beneficial.²⁷

Even outside hospital an anorexic is subject to significant pressure from friends, family and society in general to seek treatment, and may include the threat of committal if she will not submit 'voluntarily'. What this approach fails to recognize is that many anorexics regard their condition not as an illness but as an identity and a way of life, one that provides significant benefits despite the pain it involves.²⁸

Although the exact aetiology of anorexia is unknown, biological, genetic, and psychosocial factors are all thought to play a part, and this biopsychosocial model forms the basis for current treatment practices. Vandereycken W. & Meerman R. <u>Anorexia Nervosa: a Clinician's Guide to Treatment.</u> Berlin-New York: Walter de Gruyter; 1984. For fuller discussions of physical, psychological and social contributions see Giordana S. <u>Understanding Eating Disorders: Conceptual and Ethical Issues in the Treatment of Anorexia and Bulimia Nervosa</u>. Oxford: Oxford University Press, 2005; chapters 4-8; Gillett G. <u>The Mind and its discontents</u> (Second Edition). Oxford: Oxford University Press, 2009; Chapter 11: 'I eat therefore I am not'; p281-305.

P281-305.

24 Morris J. & Twaddle S. 'Anorexia nervosa.' *BMJ* 2007; 334:894-898; Herpetz-Dahlmann B & Salbache-Andrae H. 'Overview of treatment modalities in adolescent anorexia nervosa.' *Child Adolescent Psychiatric Clin. N. Am.* 2009; 18(1):131-145; Yager J., *et al.* Practice Guideline for Treatment of Patients With Eating Disorders (Third Edition). APA 2006.

25 If food avoidance, purging, excessive exercise etc are relaxed, the body will begin to return to its

²³ If food avoidance, purging, excessive exercise etc are relaxed, the body will begin to return to its physiologically normal weight.

Giordana, supra, n23 p204; MacDonald C. 'Treatment Resistance in Anorexia Nervosa and the Pervasiveness of Ethics in Clinical Decision making.' *Can. J. Psychiatry* 2002; 47:267-270.
 Guarda AS. *et al.* 'Perceived Coercion and Change in Perceived Need for Admission in Patients

Guarda AS. *et al.* 'Perceived Coercion and Change in Perceived Need for Admission in Patients Hospitalized for Eating Disorders.' *Am. J. Psychiatry* 2007; 164:108-113; Watson TL. *et al.* 'Involuntary Treatment of Eating Disorders.' *Am. J. Psychiatry* 2000;157: 1806-1810; Tan 03a, supra, n9.

²⁸ Some eating disorder specialists even go so far as to contend that it is not a mental illness at all. Simona Giordana states that: "Eating anomalies are not the symptom of an underlying mental disorder, as it is often argued." Supra, n23 p8.

It has been argued, that in certain situations, an anorexic might justifiably (and competently) refuse treatment while freely acknowledging the risks involved. Although the majority of anorexics do not pursue starvation as a means of suicide, thinness may become so important that they prefer to die than accept treatment.²⁹ In other cases, sufferers feel trapped in an uncontrollable nightmare from which they can never recover, where both living with the illness and gaining weight are equally unbearable. For such patients, the refusal of food (and consequently treatment) takes on an additional significance; starvation becomes both the cause of the anguish and the potential solution. This is the paradox of end-stage anorexia, and provided the patient's assessment of the low probability for recovery is accurate, such a determination could be regarded as a logical response to a tragic situation. Perhaps such decisions ought to be respected either because they are competently made, ³⁰ or out of compassion for the patient's suffering.³¹

Most anorexic patients are not attempting suicide by starvation, however, but continue to engage in behaviour that seriously endangers their life.³² This is generally taken as a sign that they are both mentally ill **and** incompetent to make decisions regarding their personal welfare. Despite this, anorexia is distinguished by the fact that patients retain capacity with many aspects of daily life with the exception of issues regarding weight and eating.³³ If an end-stage anorexic's choice to die can, under certain circumstances, be regarded as competent, why not an identity anorexic's decision to live as she is, provided she understands the risks such a lifestyle presents?

2.2 Anorexia and personal identity

Identity is a complex and much-debated concept, with physical, psychological and social components. In practical, day-to-day terms, I regard myself as 'me' because I have a sense of being a physical and psychological entity distinct from others, one whose emotions,

²⁹ Beumont P. & Vandereycken W. In <u>Treating eating disorders: Ethical and personal issues.</u> Vandereyken W & Beaumont P (Eds). New York: Athelone Press, 1998; Chapter 1: 'Challenges and risks for professionals'; p1-30; <u>Anorexics on anorexia.</u> Shelley R (Ed.) London: Jessica Kingsly Publishers, 1997.

A position espoused by commentators such as Rebecca Dresser (supra, n5) and Heather Draper ('Anorexia Nervosa and respecting a refusal of life-prolonging therapy: a limited justification.' *Bioethics* 2000; 14(2):120-133).

³¹ Giordano S. 'Anorexia Nervosa and refusal of naso-gastric treatment: a response to Heather Draper.' *Bioethics* 2003; 17:1467-8519.

Anorexia nervosa has a mortality rate of up to 20%, the highest of any mental disorder and frequently through suicide by *other* means. Papadopoulos FC. *et al.* 'Excessive mortality, causes of death and prognostic factors in anorexia nervosa.' *Br. J. Psychiatry* 2009; 194:10-17.

³³ Gutheil, TG. & Bursztajn H. 'Clinicians' guidelines for assessing and presenting subtle forms of patient incompetence in legal settings.' *Am. J. Psychiatry* 1986; 143:1020-1023.

thoughts and bodily sensations are experienced a very particular way. I have memories that trace my life backwards in time, and hopes, expectations and plans for the future. It is this ability to construct a coherent story of who I am (or want to be), how I got here and where I want to go that forms the core of what it means to be 'me'. What I value and the way I perceive myself is shaped by my upbringing, past experiences and interactions with others, and I may present different 'selves' to others at different times or in different social situations.³⁴ Although such relationships are fluid and malleable, there remains a central "I" that experiences and interprets the world around me.

Because of its uniquely subjective nature, personal identity is a central consideration when considering questions of autonomy and decision-making. In the words of John Stuart Mill (one of the sources used by Beauchamp and Childress in deriving the principle of autonomy), "[i]f a person possesses any tolerable amount of common sense and experience, his own mode of laying out his existence is best, not because it is the best in itself, but because it is his own mode." In other words allowing me to exercise control over my life in a way that is consistent with my own values, wishes and desires, is best *for me* because it is what I want.

Although some psychiatric conditions clearly involve a dramatic change in personality or a loss of identity (such as psychosis or Alzheimer's disease), there is little difficulty making treatment decisions based on what the 'healthy' self would have wanted rather than the desires of the patient as she is now. In the case of anorexia, however, the onset of the condition often coincides with the time that personal identity is being formed, making decisions based on what the patient's wishes would have been problematic. Some have even gone so far as to describe anorexia as an identity disorder: It is argued, for example, that eating disorders arise from a disturbance of somatic identity (the way in which an anorexic experiences or perceives her body), ³⁶ or that the patient uses body weight (which is

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This communitarian view of identity arises from considerations about moral responsibility and the relationship between ethics and the self. Alasdair MacIntyre and Charles Taylor argued that concepts of identity and what is good are dependent on social relationships. We evaluate what is right and wrong by reference to the community to which we are attached, and interpret peoples' intentions in the context of their past experience and actions. "[A]ll attempts to elucidate the notion of personal identity independently of and in isolation from the notions or narrative, intelligibility and accountability are bound to fail." (MacIntyre, A. After Virtue. Notre Dame: University of Notre Dame Press, 1984; p208.

³⁵ Mill JS. in On Liberty and Other Essays. Oxford World's Classics. Oxford: Oxford University Press, 2008; p75.

³⁶ Lorenzi P. *et al.* 'Life crisis and the body within.' *Psychopathology* 2000; 33:283-291.

both personally controllable and culturally valued) as a source of self-definition in compensation for an otherwise unclear cognitive identity.³⁷

While many people regard anorexia as an illness to be 'cured', many anorexics regard their illness in an entirely different light. Indeed, it is also well recognised that an anorexic's rigid control of her food and weight can be an adaptive response to situations for which she can find no other solutions. It may, for example, allow a 'good girl' who has strived to please everybody to exercise control over her life or assert her autonomy.³⁸ Delaying or reversing the physical changes of puberty, anorexia may be a way of avoiding the changing social and sexual expectations that accompany adulthood, ³⁹ or a response to social stereotypes of femininity.⁴⁰

The widespread perception that food and weight are the problem rather than a symptom of distress is a big disincentive for weight gain, since people assume that when the anorexic looks well, everything is resolved. If we want to act in the best interests of anorexic patients, we need to take account of the perspectives of the individuals themselves. Although few systematic studies have yet been done, patient interviews clearly show that many regard the anorexia as an essential part of themselves. They attribute psychologically important meanings to their behaviours, and regard anorexia as beneficial, meeting needs they have been unable to satisfy in other ways.⁴¹ Tightly regimented daily routines provide a sense of security and structure to daily life, which they have previously found frighteningly unpredictable. A constant preoccupation with food and weight forces all other worries and problems (such as anger, fear or the expectations of themselves or others) into the background. The rigid self-discipline provides a sense of mastery and strength, while allowing them to acknowledge and feel worthy of praise. For some, it is a way of communicating distress that they are unable to express any other way, and a way of eliciting care from others. 42

³⁷ Stein KF. & Corte C. 'Identity Impairment and the Eating Disorders: Content and Organization of the Self-Concept in women with Anorexia Nervosa and Bulimia Nervosa.' Eur. Eat. Disord. Rev. 2007; 15:58-69. ³⁸ Bruch, supra, n22 p38-56; Giordana, supra, n23 p153-155.

³⁹ See, for example, Bruch, supra, n22 chapter 4: 'How it starts'; p57-71; Crispe A.H, <u>Let Me Be.</u> London: Academic Press; New York: Grune & Stratton, 1980.

⁴⁰ This feminist interpretation is the focus of Susie Orbach's <u>Hunger Strike</u>. Harmondsworth: Penguin, 1993. ⁴¹ Hilde Bruch, for example considered that her patients' "relentless pursuit of thinness" arose from the need to establish their identity and effectiveness by controlling their own bodies, and reported that even after recovery: "Most feel that without it they might have stuck with their overdependent attitude toward the family, or might have become mentally sick in other ways." Supra, n22 p147-148. For more on this subject see chapters 3-5; Giordana, supra, n23 chapters 5-9; Orbach, supra, n40 chapters 5, 8-9.

⁴² Tan JOA. *et al.* 'Anorexia Nervosa and Personal Identity: The accounts of patients and their parents.' *Int. J.* Law Psychiatry 2003; 26:533-548; Rich E. 'Anorexia dis(connection):managing anorexia as an illness and an

Over time, anorexia can even become integrated into personal identity. Respondents to a questionnaire posted on pro-eating disorder sites, for example, describe their eating disorder as 'an existential state that pervades every aspect of thought, perception and action, and is thus felt to be inseparable from one's identity.'43 Further reinforcement (albeit unintentional) is provided by medical professionals (with a diagnosis of 'anorexia' you become an illness rather than a person)⁴⁴ and through relationships with other anorexics. There is a communality of experience that makes one a member of a highly distinctive social group. Let me illustrate this with reference to my own narrative:

One of the strangest (and most frightening) experiences of my life has to be group counselling, surrounded by a dozen other women whose physical appearance, body language and mannerisms made me feel like I was looking in a mirror. Even more disturbing was the fact that another woman would open her mouth and speak the thoughts in my own head. For the first time I had found a peer group to which I belonged, people who truly knew what I felt and why I behaved as I did, who experienced the same fears and triumphs and who understood. Other people regarded us with a curious combination of revulsion and fear, fascination and admiration. They thought it was about food and weight, that if we reached an appropriate BMI that we would be 'normal' like them, and didn't realize that they lived in a world that was very different to ours. We were Anorexics, and our way of life was normal to us, regardless of what the scales (and the doctors) said.

From the health carer's perspective, even when the importance of anorexic behaviour or even anorexic identity is recognised, it remains something to be altered. For example Hilde Bruch, an acknowledged expert in the field of eating disorders, while recognising the importance of the disorder to her patients considered that the creation of a 'new personality' was the mark of true recovery. 45 Similarly, Suzie Orbach lists the third objective of treatment as 'restarting the development of self.'46 Bruch and Orbach identify precisely the reason why treatment resistance is so common among anorexic patients, however, because

identity.' Sociology of Health and Illness 2006; 28:284-305; Csipke E. & Horne, O. 'Pro-Eating Disorder Websites: Users' Opinions.' Eur. Eat. Disord. Rev. 2007; 15:196-206.

⁴⁴ It is a sad irony that an anorexic may attempt to regain control and individuality by turning this distinction on its head to assert: "This is not an illness but who I am."

⁴⁵ Bruch H. 'Anorexia Nervosa: Therapy and Theory.' Am. J. Psychiatry 1982; 139:1531-1538.

⁴⁶ Orbach, supra, n40 p110.

for them 'cure' means relinquishing meaningful and important aspects of their lives, and even their very sense of themselves.

CHAPTER THREE: ETHICAL ISSUES

Although there is considerable disagreement about the relationship between law and ethics, ⁴⁷ in practice they tend to be interdependent. ⁴⁸ The fact that the law recognises that it is sometimes necessary and appropriate to treat people in the absence of consent indicates our society regards this as morally acceptable (provided it is done in the best interests of the patient). The question of *when* it is ethical to use compulsion is thus as relevant to legal as it is to medical decision making. In this chapter I will establish the ethical conditions under which coercive treatment is permissible, and how such a framework can be applied to endstage and identity anorexia. Because questions of if, and when, compulsion should be used on anorexic patients arise in a medical setting, my analysis is principlist in nature: The circumstances in which non-consensual intervention is justified depends upon the relationship between respect for autonomy and the principles of non-maleficence and beneficence. This same analytic framework can also be applied to the MHA and the PPPRA, to ensure that compulsory treatment of anorexic patients is both legally consistent and ethically acceptable.

3.1 Beneficence and non-maleficence.

Non-maleficence is perhaps best summed up in what is commonly recognised as the primary injunction of the medical profession: "First do no harm." Although 'harm' can be very widely defined, ⁴⁹ for the purposes of this dissertation I will refer to harm (and benefit) in the context of actions that adversely impact on the physical or psychological wellbeing of both the patient and others, such as friends or family, whose lives are affected by the illness.

The principle of beneficence rests on the idea that it is morally good to do things for the benefit of others.⁵⁰ The extent to which we are *obliged* to help others is a subject of considerable philosophical debate, but the therapeutic relationships that arise in medicine

⁴⁷ At one extreme, some consider that the law defines and enforces social morality, at the other, that morality defines law.

⁴⁸ For example, we give great importance to the idea of competence with respect to medical (and other) decisions, because it is considered directly related to autonomy; a person who is unable to make a competent decision is by definition not fully autonomous. Whether a person can have impaired autonomy but retain competent to make treatment decisions is a question to which I will return later.

competent to make treatment decisions is a question to which I will return later.

49 At the most trivial end, I could harm you by hurting your feelings, at the most serious kill you slowly and painfully. For a discussion of other, more abstract harms see Joel Feinberg in Harm to Others. Oxford: Oxford University Press, 1984; Chapter 2: 'Puzzling Cases'; p65-84.

⁵⁰ By protecting other people's rights, for example, or rescuing them from danger.

place duties on physicians to promote their patients' welfare. Whilst beneficence has been equated with medical paternalism (the restriction of a person's freedom of choice in order to protect his or her welfare), and in conflict with autonomy (the principle of self-governance), arguments from beneficence justify the importance of patient self-determination on two grounds. Firstly, what *patients* consider to be in their best interests extends beyond what will benefit them medically. Other values and preferences will also be important considerations for them. A Jehovah's Witness needing a blood transfusion may refuse one, even if it means that they will die, because accepting it would condemn them to eternal exclusion from the Kingdom of Heaven. Similarly, a patient with a potentially curable cancer might reject chemotherapy for palliative care because they would rather have a reasonable quality of life for whatever time remains to them than suffer the consequences of aggressive treatment with no guarantee of success. Illness is, for the patient, one episode in the ongoing narrative of her life, and any consideration of benefit needs to incorporate both her own views on the type of life she wishes to live and her subjective experience of both illness and treatment.

Secondly, overriding peoples' autonomy, particularly when illness makes them feel helpless and vulnerable can further disempower them. Because this is likely to cause further harm, beneficence (and non-maleficence) would militate against such action.

Conversely, arguments from beneficence can also be used to justify overriding a patient's autonomous decision (strong paternalism). Beauchamp and Childress suggest such actions can be justified if:

- A patient is at risk of a significant, preventable harm.
- The paternalistic action will probably prevent the harm.
- The projected benefits to the patient of the paternalistic action outweigh its risks to the patient.
- The least autonomy-restrictive alternative that will secure the benefits and reduce the risks is adopted.⁵¹

The principle of beneficence can also override the prohibition against harm, in certain situations, provided the likely benefit of intervening outweighs the cost of doing so. 52

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⁵¹ Beauchamp & Childress, supra, n13 p283. The authors also add the proviso that intervention is only justified if vital or substantial autonomy interests are not at stake, and cite the example of the Jehovah's Witness patient as an example where strong paternalism would not be ethical. In practice, doctors (and courts) may find reasons to circumvent this.

To illustrate this point, Shelly Kagan gives the example of George, whose leg is trapped beneath a tree. The only way to save him is to amputate his leg, which is certainly a major harm, but allowing him to die would

3.2 Paternalism and autonomy

Although paternalism⁵³ and autonomy are often portrayed as being antithetical, this is an over-simplistic interpretation of the relationship between them. Paternalistic interventions are intended to benefit the person who is subject to them, and, as discussed above, the ability of a person to be able to choose what happens to them is an important factor in determining what is in their best interests. Where the two concepts come into conflict is in regard to whether autonomy is a good in and of itself, or merely one of many factors that contribute to a person's welfare.

3.2.1 Autonomy

In Principles of Biomedical Ethics, Beauchamp and Childress argue that respect for autonomy means more than just acknowledging a person's right to hold their own beliefs and values, and to make choices based on these. It also requires enabling them to act autonomously, by maintaining their capacity to make autonomous choices while "allaying fears and other conditions that destroy or disrupt their autonomous actions."54

Explaining why such respect is important, Beauchamp and Childress cite Immanuel Kant and John Stuart Mill. Kant argued that people have an intrinsic value and capacity to determine their own destiny; when we violate other people's autonomy we use them as a means to our *own* ends without regard to their own goals. Mill, on the other hand, contended that it is in the best interests of society as a whole that individuals make decisions about their own future good, provided their actions do not harm others. He considered autonomy and self-determination as synonymous, and this is the sense in which we understand autonomy in the medical (or legal or social) context today. We allow people to make all sorts of irrational or apparently unreasonable decisions about treatment (including the refusal of life-sustaining intervention) because we respect their beliefs and desires.⁵⁵ Provided our choices are made freely and with adequate information, both the *content* of those wishes and desires and the subsequent outcomes are not material to determining our

constitute an even greater harm. On balance, the overall benefit to George of the amputation outweighs the harm of being left with only one leg. In Normative Ethics. Boulder: Western Press, 1998; Chapter 2: 'Doing Harm'; p86-87.

⁵³ Literally, acting as a father would towards his children.

⁵⁴ Supra, n13 p125.

⁵⁵ Kant regarded rationality as the basis of human dignity and a higher ideal than the pursuit of happiness, and autonomous decisions as based reason, not emotion or self-interest. For a more detailed discussion of Kantian and Millian definitions of autonomy and their relevance for to psychiatry see Matthews E. 'Autonomy and the psychiatric patient.' J. Applied Philos. 2000; 17(1):59-70.

autonomy.⁵⁶ This procedural definition of autonomy is closely allied to the legal concept of competence, which is intended to determine whether our decisions are autonomously made, rather than whether they are sensible or normal, and the two terms are often used interchangeably.

3.2.2 Strong and Weak Paternalism

Although for many people medical paternalism has become synonymous with the abuse of power, it is founded in the principles of beneficence and non-maleficence. Paternalistic interventions (where treatment decisions are made on the patient's behalf) restrict that person's freedom, either by being carried out independently of, or in contradiction to, his or her wishes. They are not carried out maliciously but are intended to protect the welfare of the person whose actions or choices are being limited. The second principle of the Hippocratic Oath states that treatment 'shall be for the benefit of the patients according to my ability and judgement and not for their hurt or any wrong'. Doctors in New Zealand no longer take this oath, but the underlying duty of a physician remains to act in the best interests of his or her patients. If we consider freedom of choice more important than (or necessary for) ensuring an individual's welfare, the patient ought to determine where his or her best interests lie. On the other hand, if other considerations such as the maximisation of a person's physical wellbeing are given equal or greater weight than self-determination, a physician may be justified in acting to prevent a person making a dangerous or irrational choice.

Joel Feinberg has distinguished between two forms of paternalism. Strong paternalism allows (under certain circumstances), the restriction of a person's autonomy, while weak paternalism justifies restricting another's freedom of choice *only if* his or her autonomy is in some way compromised.⁵⁸ Under the strong version of paternalism (at least in the medical situation), it is the doctor rather than the patient who determines what is best. A patient's wishes can be legitimately overridden in order to prevent her from seriously harming herself, or to ensure she does not deny herself important benefits. Strong paternalism could even extend to preventing the negative consequences of foolish or

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⁵⁸ Feinberg J. 'Legal Paternalism.' Can. J. Philos. 1971; 1:105-124.

⁵⁶ They may be important in other ways, however, particularly if our actions may harm others.

⁵⁷ This is also, perhaps, the Hippocratic basis of the idea of non-maleficence, which does not appear anywhere else in the Oath (despite popular belief that 'primum non nocere' is Hippocratic, it isn't).

imprudent behaviour.⁵⁹ Weak paternalism, in contrast, allows intervention to protect a person from self-harm only if she is unable to make a competent decision, or if it is necessary in order to assess whether she is acting autonomously. In all other instances, it is the patient's right to make her own determination of where her best interests lie.⁶⁰ This latter form of paternalism is recognised in current legal and medical practice. We give great importance to the idea of competence with respect to medical (and other) decisions, because it is considered directly related to autonomy; a person who is unable to make a competent decision is by definition not fully autonomous.⁶¹

3.2.3 Is compulsory treatment for anorexia justified under strong paternalism?

Strong paternalism assumes that there are goods that are as, or more, important than autonomy, and if on balance a person's welfare-life, health and wellbeing-will be protected by providing treatment despite her objections, restricting her autonomy is the right thing to do. This is not to say that autonomy is not an important consideration, insofar as exercising it promotes her welfare (for example active participation in therapy can promote remission of or recovery from psychiatric illness), but it is secondary to the need to protect her health. Compulsory treatment can thus be justified in all cases where the overall benefit to the patient in terms of her life and health outweighs the harm caused by restricting her autonomy. Although strong paternalism does not justify the enforced use of futile or antitherapeutic treatment, the determination of whether treatment is likely to be beneficial or not rests on a clinical judgement of efficacy rather than the patient's decision about what does (and does not) constitute a life worth living. This could override treatment refusals by all anorexics, regardless of their autonomy.

⁵⁹ Rawls J. <u>A Theory of Justice</u>. Oxford: Oxford University Press, 1972; p249.

⁶⁰ Restriction another person's autonomy *can* be justified if it will harm others.

Whether a person can have impaired autonomy but remain competent to make treatment decisions is a question to which I will return later.

question to which I will return later.

62 What goods are more important than autonomy will depend on context. While strong paternalism in medical (and public health) focuses on physical and psychological health, a priest might be more concerned with spiritual well being, for example.

⁶³ Important considerations include the extent to which her health and quality of life are threatened by her behaviour, availability and efficacy of treatment, and the length of time compulsion is likely to be necessary until the welfare benefits are achieved or she voluntarily agrees to treatment. This may be particularly true for an anorexic, since the eating disordered behaviour often represents the only way she can feel in control of her life.

3.2.4 Is compulsory treatment for anorexia justified under weak paternalism?

If we assume that autonomy has a high intrinsic value in and of itself, acting in such a way as to interfere in a person's life choices would constitute a major harm. As Jonathan Glover points out:

[M]any of us would not be prepared to surrender our autonomy with respect to the major decisions in our life, even if by doing so other satisfactions were greatly increased...Even in small things, people can mind more about expressing themselves than about the standard of the result. And, in the main decisions of life, this is even more so.⁶⁴

When this consideration is added to the fact that respect for autonomy is also likely to contribute to that person's overall welfare, compulsory treatment (unless it is life saving) is almost certain to do far more harm than good. Not only would this violate the principle of non-maleficence, it cannot be justified by appealing to beneficence, because overriding autonomy would not be in the best interests of that person.

If, however, a person's ability to make genuinely free and reasoned decisions is impaired (for example by illness or injury), the normative value of self-determination (doing what you want) decreases. When a patient's autonomy is compromised, the onus for deciding what action is necessary to ensure her health and wellbeing shift towards the doctor, judge, or family members who step in to make decisions on her behalf. Under these circumstances, weak paternalism would permit non-consensual intervention if the patient were likely to benefit from the treatment. While strong paternalism can justify the compulsory treatment of any anorexic provided it is not futile or counterproductive, soft paternalism would only permit compulsory treatment for an anorexic patient if it can be shown that she is unable to make autonomous decisions on her own behalf, and that such intervention is likely to help. The latter approach seems to better balance autonomy, non-maleficence and beneficence than strong paternalism, and suggests that compulsory treatment of an anorexic patient is ethically permissible if and only if:

1. She is treatment resistant (a person who is willing to accept treatment does not require coercive measures to get her to do so).

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⁶⁴ Glover J. <u>Causing Death and Saving Lives.</u> London: Penguin, 1990; p80-81.

Although these decisions should be guided by what the patient would most likely to have decided had she been able to do so.

- 2. Her health and welfare are seriously endangered (if the treatment in question were for only trivial problems, the benefits would be only trivial, and so the question of coercion would probably not arise).
- 3. Potentially effective treatment is available and would not be undermined by the use of compulsion. (This is an ethical requirement of both beneficence and non-maleficence).
- 4. The ability to make relevant decisions in an autonomous manner is compromised by her illness. (This is a demand of autonomy i.e. respect my choices provided they are competent).

I shall refer to these as 'the criteria for justified compulsory treatment' or just 'the criteria' in what follows. They amount to a soft paternalistic justification for compulsory assessment/treatment in the sorts of cases discussed in this dissertation.

3.3 Ethics and end-stage anorexia: The right to die

Regardless of an anorexic's willingness or otherwise to undergo treatment, the process of recovery is a traumatic and distressing. Far from being irrational, treatment-resistance is quite reasonable when seen from the anorexic's point of view, in the same way that we can understand why a cancer patient would prefer not to accept the side effects of chemotherapy. To illustrate my point, I would like to conduct a thought experiment. Imagine that you suffer from an intense, phobic fear of snakes. In New Zealand this would not be a major problem. Snakes are easily avoided, and you can live quite happily despite this unfortunate mental quirk. Now mentally transport yourself to India, where snakes are an occupational hazard of life. You are not only unable to relax or enjoy the normal pleasures of life, work and family for fear of unexpectedly encountering one of these nightmarish creatures, you are locked in a room full of snakes three times a day, every day, with no hope of escape. Even knowing this was meant to cure you through desensitisation, such intellectual understanding is of little defence against the intense, primal terror that you are currently experiencing. This is what it is like in an anorexic inpatient treatment unit. You are confronted with the proximal challenge of having to put food in your mouth. While being constantly supervised

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⁶⁶ And not just any food, *forbidden* food.

to ensure you do: Not only are you breaking all the anorexic rules, other people *know* that you are. In addition, you are prevented from carrying out any of the activities that allow you to compensate for eating, so you live with the constant knowledge that every calorie that you take in will eventually manifest itself physically as weight gain. Now not only will the people who see you eat know that you do, so will everybody else. They will see and hate you for the greedy, lazy, selfish person you really are, or decide you are fine and have no problems and expect you to cope on your own.

In the short term this can be survived, if there is a genuine hope that things will eventually get easier. What if, however, you go through the process of weight gain and therapy (with its accompanying guilt and self-loathing), only to find all the rest of the thoughts and feelings remain even though you are 'healthy'? At least losing weight again means that you return to familiar (if still tortuous) territory. The more cycles of this you go through, the less possible escape from the constant nightmare you live in seems, and the harder it is to endure the slow, painful process of starvation. For some people, death feels like the only solution. Far from being a benefit, treatment only serves to worsen their suffering, and the principles of beneficence and non-maleficence suggest that the use of compulsion is wrong in such situations.

3.3.1 Death as an autonomous choice

It could be argued that because the *reason* that weight gain is unbearable is rooted in the illness, the anorexic's decision to refuse life-sustaining treatment is not freely made and thus she is not acting autonomously. Others contend that such a decision can be regarded as competent because an end-stage anorexic considers the burden of therapy (and its consequences) are too much to bear.⁶⁷ Even if she is unable to make competent decisions regarding food and weight, she can still judge her quality of life.⁶⁸ Heather Draper suggests the following description of a person competent to withdraw from treatment:

- The patient refusing treatment has been afflicted beyond the natural cycle of the disorder (1-8 years).
- She has already been force-fed on previous occasions.
- She is competent to make decisions regarding the quality of her life.

⁶⁷ I use the term 'competent' here because this is the standard test for autonomy adopted by the medical (and legal) profession. Whether this is an adequate reflection of how we understand autonomy is a question I will return to in chapter four.

⁶⁸ See, for example, Draper 00, supra, n30; Dresser 84, supra, n5.

- She has some insight into the influence anorexia has over some aspects of her life.
- She is not at 'death's door' (ie her mental facilities are not compromised by extreme starvation).⁶⁹

One problem with this proposal is that it does not take full account of the *quality* of treatment.⁷⁰ Other factors (such as the exhaustion of all available therapeutic options) need to be taken into account. These considerations are consistent with respecting the end-stage anorexic's autonomy; she rejects treatment not because she would rather die than recover but because she finds her life with and without treatment unbearable. If, however, all available therapeutic options have been tried and failed, and the patient's assessment of her situation is realistic, her choice should be respected, out of respect for autonomy and the principle of beneficence.

3.3.2 *Is autonomy (always) relevant?*

Perhaps the greatest difficulty facing clinicians, family members and loved ones when an anorexic refuses treatment is the fact that anorexia is not necessarily a fatal disease.⁷¹ There is a simple way to prevent death, and that is to provide the person with food. ⁷² By respecting her refusal of life-sustaining treatment, we make her death inevitable, and eliminate any possibility that recovery might be possible at some future point. As Simona Giordana points out, if we accept Draper's (and Dresser's) contention that anorexic patients can competently refuse life-preserving treatment, the fact that they do not claim that all competent anorexics should be allowed to do so suggests that factors other than the right to self-determination need to be taken into consideration. The fact that in some situations we feel it is right for a chronically ill anorexic be allowed to die is influenced not only by our respect for her autonomy, but also by our sense of compassion. Heather Draper speaks of

⁶⁹ Supra, n30.

⁷⁰ In my case, it was over 12 years before I began to recover. Although I had undergone a variety of interventions at different times, including behaviour modification (a reward/punishment system), Freudian, group, individual, occupational and cognitive behavioural therapy, the successful treatment programme was far more comprehensive than any I had previously experienced. For this reason, I am unwilling to accept hard and fast criteria such as Draper's.

⁷¹ Giordana (supra, n23) draws a distinction between the causes of anorexia and its *symptoms*: To say 'you don't eat because you have anorexia' is tautological if the diagnosis of anorexia is made on the basis that you don't eat. However because the exact aetiology of anorexia is unknown it is a syndrome that can only be described in terms of its symptoms. Arguments over cause and effect are at this point unhelpful, and for the purposes of our compulsory treatment laws, irrelevant.

⁷² Although under some circumstances all attempts to do so may fail, as is shown by the case of LB discussed below

'palliation', while Rebecca Dresser makes the analogy between the chronic anorexic and a terminally ill patient. Such terminology suggests that what is relevant is not that the patient would rather die than live as she is, but that intervention, forced or otherwise, is unlikely to provide improvement in her quality of life. If this is right, it seems impossible to justify under either strong or weak paternalism; the principle of non-maleficence imposes an obligation not to carry out actions that are likely do more harm than good. Even if there are reasons to question a person's autonomy,' life-sustaining treatment is not obligatory if its burdens outweigh the benefits to the patient, even if she is not terminally ill. Applying the ethical criteria described earlier, compulsory treatment of end-stage anorexics is not permissible. Although such patients meet the first two criteria (they are treatment resistant and their life is endangered), the third condition (that effective treatment be available) is not satisfied. Enforcing futile or anti-therapeutic treatment violates the principles of non-maleficence and beneficence, and is thus prohibited, irrespective of the patient's autonomy. The critical question then becomes *when* is the end-stage reached?

One method for assessing both patient competence and treatment prospects is discussed in chapter five. In other situations, treatment futility may be obvious. Take, for example the situation outlined *In the Matter of LB*.⁷⁴ LB had a 19-year history of chronic and treatment-resistant anorexia nervosa, which began when she was 14. She had undergone a wide variety of treatments (in and out-patient): one-to-one psychotherapy, behavioural modification (both strictly enforced and self-regulated), advance consent through 'contract', compulsory treatment under the MHA, and force-feeding. All available therapeutic options had been explored and proved unsuccessful, with any gains being temporary and her 'maintenance' body weight steadily dropping. Her overwhelming fear of weight gain was such that she fought any treatment, to the extent that on her last admission (where she was fed, under restraint, by nasogastric tube and infusion), she used more energy resisting food than she received from it.⁷⁵ Every therapeutic approach had been explored and proved unsuccessful, and the responsible clinician considered not only that treatment was futile, it was worse than the illness. He suggested that she be allowed to spend her remaining time with her family, with any care palliative only. Her mother supported this

⁷³ Principles of Biomedical Ethics, supra, n13 p214.

⁷⁴ MHRT/NR No 848/2000, 15 December 2000.

⁷⁵ Her resistance took the form not only of physically and verbally fighting her treatment team, but also self-harming behaviour such as vomiting and banging her head on the floor.

recommendation. As tragic and rare as this situation is (or so I hope), sometimes we may need to accept that it is better to let a person die, even if that death is avoidable.

3.4 Ethics and anorexic identity: The right to live

Although life-saving intervention for an acutely ill anorexic patient may be both legally and morally permissible (or even obligatory), ⁷⁶ justifying longer periods of involuntary treatment is ethically challenging. The clinical reality is that a number of patients will continue for some time to resist attempt to normalise eating habits or gain weight to a 'safe' level. In addition, there are significant medical risks involved in re-establishing a normal diet when a person's metabolism is calibrated to starvation mode (re-feeding syndrome) that needs to be carefully monitored. Extended compulsory treatment can be justified if the patient's autonomy and ability to make treatment decisions is compromised by her illness (and/or the physical effects of starvation). Factors such as lack of insight into the degree of physical danger the patient's behaviour places her in (or the denial that there is anything wrong) are frequently cited in justifying compulsion. Likewise, an overwhelming fear of gaining weight (or the misperception of herself as fat), or ambivalence towards treatment are regarded as signs of disordered volition, perception or cognition that compromise her ability to make decisions on her own behalf.⁷⁷

Not all anorexics reject therapy for these reasons, however. Some of them freely acknowledge that their thinking about food and weight is not 'normal', but prefer to live as they are (with all of its difficulties) than go through the physical and emotional upheaval of a treatment that may or may not be effective. If an anorexic declines treatment because, on balance, the uncertain prospects of returning to a 'normal' life are outweighed by the potential loss of self-identity (and the benefits that come with the illness) is this necessarily an incompetent decision or an indication she is not acting autonomously? Medical patients can legitimately reject treatments (even those with a high chance of success) on any or no basis whatsoever. For an anorexic refusing treatment, the fact that her choice of ends

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⁷⁶ This is legally permissible under the doctrine of necessity, and can be regarded as being in her best interests, at least until her autonomy (or lack thereof) and own wishes can be established.

At least to make the decision to *reject* treatment. The same distinction doesn't seem to apply to a decision to *accept* treatment even if this is the result of implicit or explicit coercion on the part of friends, family or clinicians.

appears irrational is not in itself grounds for compulsion unless it can be shown it is different from a person refusing cancer treatment (for example) in some morally relevant way.⁷⁸

3.4.1 Harm to self

One objection might be that in choosing to remain anorexic, she is causing herself considerable harm. Extended periods of starvation, excessive exercise and purging cause significant physical damage, including muscle wastage, cardiac dysfunction and damage, impaired immune function, loss of bone density, infertility and even brain damage. In addition, social isolation, the strain of living the strict eating and exercise regiments, and physiological factors lead to depression. If left untreated, the mortality rate is 20%, but can be reduced to 2-3% with appropriate therapy, and many of the effects of starvation are reversible.⁷⁹ Is this a sufficient justification for intervening on grounds of beneficence?

When it comes to self-harm, our society seems to operate a double standard. Those who eat themselves to morbid obesity are not required to undergo involuntary weight loss despite the health complications to which their conditions lead. Although we make moral judgements about their greed or lack of self-discipline, we do not regard them to be mentally ill (although perhaps we should consider that overeaters deserve assistance just as much as under-eaters). Other self-endangering behaviours are even considered praiseworthy. Such admiration extends beyond those who risk themselves for the public good, such as fire-fighters and soldiers, to those who do such apparently irrational, dangerous and physically tortuous things such as climbing the world's highest mountains or crossing the Antarctic on tractor (almost certainly against their own physical interests). Rather than disapprove of their actions or consider them mad, we regard such individuals as national icons. They achieve feats that speak to our national identity, or which we ourselves aspire to. Their reasons for doing so are seldom questioned. I f we accept an anorexic makes her decision in full knowledge of these risks, how is this different to any of the examples listed above?

Based on this argument, the fourth criterion necessary to justify the use of compulsion is not

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⁷⁸ The benefit provided or the harm prevented must also outweigh the psychological harm caused by loss of independence. Rebecca Dresser (supra, n5) maintains that the *only* point at which intervention is justified is when a patient is physiologically endangered, because there is no way of predicting based on psychological criteria that an anorexic will not, at some point, accept food. Anything else would be both counter-therapeutic and an indefensible infringement on her autonomy.

⁷⁹ Morris & Twaddle 07, supra, n24.

⁸⁰ The difference in value judgements probably reflects the degree to which we can place ourselves in the same position. Eating to excess is something most of us have done at some stage, while starvation is slow, hard and painful. These views are also culturally influenced (gluttony = sin or lack of control, ironically exactly those things the anorexic is striving to escape from).

met. Rescuing her from herself, an act of beneficence, infringes upon her autonomy for no guaranteed benefit, and her wishes ought to be respected.

3.4.2 Justice

Although not directly related to questions of whether it is ethical to use compulsion on an individual patient (and thus not part of the criteria outlined earlier), there are wider questions of social justice that are also relevant. Another objection to forcing a resistant anorexic into treatment is that it is an unfair use of a limited health budget. An anorexic that refuses therapy may still require considerable intervention in order to maintain her lifestyle (for example regular hospital admissions for re-feeding if her weight reaches a critical level). Even though the identity anorexic is only temporarily occupying a treatment bed, she is potentially preventing another patient who both desires, and will benefit from, access to a very limited health resource.

This is not a valid argument. Firstly, a patient refusing other medical intervention (for example chemotherapy or organ replacement) won't necessarily place any less of a strain on resources. His or her condition may require ongoing management (or at the very least palliative care) that would have been unnecessary if more aggressive treatment had been accepted. If there is a moral distinction to be made between this patient and our anorexic, it is not here. In fact, by signalling in advance that she will accept only limited intervention, the lifestyle anorexic may benefit other, more compliant patients. As stated earlier, expending resources on enforced treatment when the patient will derive no benefit is wasteful and prevents others who are willing to accept therapy from accessing those same services. Secondly, our healthcare system is predicated on a no-blame model of distributive justice. Rather than deciding who is 'worthy' or 'deserving' of treatment, basic life-preserving services are (supposedly) provided to all those who need them. The drunk driver is treated in exactly the same way as the occupant of the car that he ran into, the woman burnt in the P-lab explosion shares a ward with the innocent passer-by who was accidentally caught in the explosion.

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⁸¹ Given the likely public resistance to the idea of living with anorexia as a valid choice, she may actually advance the case for increasing accessibility and funding for therapeutic programme by highlighting importance of early intervention as a way of preventing anorexics becoming entrenched in their 'ill' identity.

3.4.3 Harm to others.

One of the difficulties in determining when (or whether) to compel an anorexic to accept treatment is the fact that anorexia is regarded as only harming the patient herself. If this is the case, we are only justified in intervening if we can show that her autonomy is compromised. Respect for an individual's autonomy is, however, limited to actions that do not harm others, and there are reasons to consider anorexia as damaging other people (in particular close family members), and also wider society. One point that emerges from a relationship-based approach to ethics is that the interests of friends and family are also morally relevant. Anorexia can have a devastating effect on those around the patient, and for them the person they know has been subsumed by a hostile stranger. The grief and distress of watching a loved one starve cannot be underestimated, and needs to be balanced against the interests of the anorexic herself.

In addition, we live in a society where dieting is not only considered a normal behaviour it is associated with a highly successful commercial industry. The incidence of eating disorders in the Western world is increasing rapidly, and the burgeoning number of pro-anorexia web sites suggests that there are a significant number of women who wish to remain anorexic, and who even compete to see who can be the thinnest, starve the longest or eat the least. 82 Indeed it could be argued that we collectively owe the anorexic a duty of care because we have created a society in which contributes to, even encourages her lifethreatening illness.

Although these concerns are not in themselves justification for overriding an anorexic's choice to refuse treatment, they are a potential consequence of accepting anorexia as a lifestyle, and need to be considered in the context of their social as well as personal implications.

3.4.4 Anorexic autonomy revisited

The most instinctive reason most of us would give for feeling uncomfortable with the idea that an anorexic could legitimately choose to reject treatment is a sense that her autonomy is in some important sense impaired by, or as a consequence of, her illness (satisfying the fourth criterion necessary to justify the use of compulsion). This raises the question of what we mean when we talk about autonomy.

⁸² Cipske & Horne 07, supra, n42.

3.4.4.1 Autonomy as freedom of choice

As discussed earlier, our social, legal and medical systems are predicated on a Millian idea of autonomy as self-governance, the right to act in accordance with our own wishes without considering the *content* of those desires that influence our choices. What, however, about an anorexic whose identity is defined by her illness? Her formal decision-making process may be intact (she understands the nature of her illness and the potentially life-threatening consequences, but on balance prefers to remain as she is rather than risk losing her sense self) but her choice is heavily influenced by the *content* of her thoughts and the unusual importance she attaches to weight and related anorexic behaviours. 83 One reason for questioning whether a person could genuinely choose to live with anorexia is that the fear of getting fat and/or the anger and shame associated with weight gain prevents her from accepting intervention. Her desire to avoid the unpleasant short-term consequences of treatment prevents her from acting on any higher order preference to live without the disorder.84 In judging her as non-autonomous, we are thus adopting a substantive rather than a *procedural* definition of autonomy. Yet other medical patients can refuse treatment without us asking them to justify their decision. What is it that is substantially different about the factors that influence an anorexic compared to other people?

Perhaps what distinguishes mental from physical illnesses is that they affect the way we 'are'. Those with psychiatric illnesses not only have wishes, preferences, beliefs and desires that differ from what the majority consider 'normal', they did not hold these beliefs *before* they became ill, or would not do so were it not for the illness. In this case, intervention could be justified by appealing to what the anorexic would have wanted *prior* to becoming ill. When the onset is pre- or peri-adolescence, autonomy is restricted in a different way. An anorexic may be unable to imagine having any identity other than that she has now, because she has never experienced a more fully developed sense of self – in which case she is unable to make a truly informed decision about whether to accept

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⁸³ In Cipske and Horne's study of pro-eating disorder website users, even the minority of respondents who considered anorexia (or bulimia) a way of life admitted that their eating disorder was not a lifestyle in the superficial sense of a set of freely chosen behaviours that they could discard at will, but as an all-pervasive influence on their thought, perception and action. Many added that it had progressed *from* a disorder to a lifestyle.

⁸⁴ Gerald Dworkin discusses the hierarchy of desires and how these relate to autonomy in <u>The Theory and Practice of Autonomy</u>. Oxford: Oxford University Press, 1988; Chapter 1: 'The Nature of Autonomy'; p3-20. He would regard the inability of the patient to adjust her first order motivation to reflect her higher-order preference as a symptom of impaired autonomy. The MHA would consider this a disorder of cognition.

85 Matthews 00, supra, n55.

treatment or not. Here a surrogate decision by her parents or guardians might be appropriate substitute for informed consent, and they would almost certainly opt for intervention.

People change their values and preferences for many reasons, however, and for an illness like anorexia, for which the underlying physical causes are unclear, and which is influenced by social and environmental factors it may be difficult to determine how anorexic's choices are less free than other people's. One could contend that the values driving an anorexic's treatment resistance arise from the condition (anorexia) but this returns us to the tautological position whereby the condition consists of those same thoughts and values. Yet many of these thoughts and values are derived from a society of excess in which we are constantly bombarded with warnings of a burgeoning obesity epidemic, where thinness is not only an aesthetic and morally praiseworthy objective, it is very much a mark of social status. Nor is it clear that the *benefits* the patient derives from her illness, such as the care and attention she receives, or the diminution of responsibility or expectation she is under, are pathological. These are things that many people would regard as advantageous or at least wish for at certain points during their life.

On the model of autonomy (as individual free will), presented here, an identity anorexic may well appear autonomous. Yet our intuition suggests her decisions are unduly influenced by her illness. Perhaps we need to adopt a different notion of autonomy, one that fits with our instinctive sense that her autonomy is in some way compromised.

3.4.4.2 Autonomy and social functionality

An alternative to the self-governance definition of autonomy reflects the fact that humans, like other primates, are social animals. We do not function as isolated individuals for whom all of our decisions are predicated only on our own desires, or perhaps more accurately our actions may reflect the interests of others.⁸⁶ This interpretation seems to best fit our current understanding of morality, since we assume that people *do* have duties towards and responsibilities for others as well as to themselves. Mill's advocacy for liberty is based on the idea that allowing the individual to choose for him or herself is in the best interests of society,⁸⁷ and that the capacity for autonomy is necessary for human well-being. He speaks of individuality as enriching and diversifying human life by "strengthening the tie which

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⁸⁶ Feinberg (supra, n49) describes these as other-regarding acts of self-interest if prompted by a desire for the well being of others as an end in itself, and indirectly self-regarding acts if intended as a means of personal benefit.

⁸⁷ 'Mankind are greater gainers by suffering each other to live as seems good to themselves, than by compelling each to live as seems good to the rest.' Supra, n35 p17.

binds each individual to the race, by making the race infinitely better worth belonging to."⁸⁸ The doctrine of individual sovereignty is, moreover, 'meant to apply only to human beings in the maturity of their faculties',⁸⁹ and we have a duty to protect those who still require the care of others from their own actions as well as those of others.

One of the distinguishing features of anorexia is that it is a singularly isolating illness. Although the ideals of self-restraint, exercise, thinness and personal discipline that an anorexic strives for may reflect prevailing cultural values, she pursues them to the exclusion of many (if not all) other aspects of her life. Food restrictions and the tendency to eat secretly and furtively mean she is unwilling or unable to participate in social situations involving food (which, in my experience, is almost all of them). Strict daily routines, exercise regimens, and the fear of having plans disrupted further preclude participation in spontaneous activities. There is a tendency to alienate friends and family when they try to intervene out of concern for an anorexic's heath and wellbeing, only to be rebuffed, leaving them confused, frustrated, angry and frightened. The physical effects of emaciation, if evident, can also be extremely upsetting and frightening. 90 If we consider autonomy (at least in part) as the ability to satisfy one's social needs in the way most humans can, anorexia represents a disruption of the normal process by which we develop as relational beings, and the anorexic 'self' arising not from self-reflection but restrained or governed by the illness. 91 What distinguishes anorexic identity from other socially or religiously influenced self identification is that it develops out of the physiological and psychological changes induced by starvation and results in self-reinforcing behaviour that resists any attempt to gain weight. Regardless of the original aetiology of anorexia, the resulting personality is shaped and constrained by the abnormal physical and mental state that result from extreme weight loss 92

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⁸⁸ Ibid, p70.

⁸⁹ Ibid, p14.

⁹⁰ I remember children running away from me in fright when I was at my thinnest, while I strode along the road proud of the fact that I looked like walking death.

Matthews 00, supra, n55. A similar idea of relational autonomy is proposed by Alfred Tauber (*Perspectives in Biology and Medicine* 2003; 46(4):484-494), who describes the self as an emergent phenomenon from the web of social relationships and obligations: Autonomy is co-ordinated with other moral principles, and autonomous choices are made in response to duties and responsibilities. An isolated person is unable to achieve full self-awareness.

⁹² Subjects of food-restriction experiments develop intense preoccupations with food, heightened emotional responsiveness (particularly irritability and negative emotionality), cognitive disturbances and a loss of interest in other areas of their life. Even when restored normal weight, food obsessions remained, frequently accompanied by a sense of being out of control around food and episodes of binge eating. Similar characteristics have been observed in concentration camp survivors with food, and anorexics frequently

The argument that anorexia somehow interferes with the 'normal' development of identity is strengthened by the fact that it often develops during adolescence, a time at which people are moving from childhood to Mill's 'maturity of faculties'. One of the striking aspects of the illness is the way in which people *lose* their individuality, becoming both physically and psychologically strikingly similar to other anorexics. Although they may find membership in the 'anorexic sisterhood', this is a highly exclusive and isolationist society. There is no way that a person who has not themselves experienced the pains and pleasures of self-denial can truly understand what it means to be anorexic. This is a shared experience that binds the anorexic to her starving sisters. It is one thing to explain to somebody the thoughts and feelings that preoccupy your existence, quite another to share them with a person who feels them herself.

Of course some religious groups are equally exclusive, and fasting in pursuit of spiritual and ascetic ideals has a long history. On the other hand, extreme forms of religious fasting were questioned even in medieval times, ⁹⁴ and today's anorexics are driven primarily by the pursuit of thinness, not spirituality. ⁹⁵ It is less akin to the adoption of the predominant religious beliefs of the society into which one is born than it is to being coopted into an exclusive cult, one that forbids its adherents to interact with the outside world, and which excommunicates those who fail to adhere to its rules. Our disquiet with such organizations can be seen in the current debate about Scientology. ⁹⁶ Nor, as discussed earlier, is membership either a deliberate decision or one that is readily changed, which

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develop bulimia. See Polivy J. 'Psychological consequences of food restriction.' *J. Am. Dietetic Assoc.* 1996; 96:589-592 for a summary.

⁹³ This further reinforces the argument that society has an obligation to take remedial action. If we create a culture that leads young people to adopt such self-harming behaviours, then we have an obligation to do something about the consequences.

Some religious ascetics admitted that their behaviour was outside their control, and self-starvation was generally regarded as a sign of possession. Other 'saintly' characteristics, such as hearing the voice of God, would today be regarded as symptoms of psychiatric illness. For a comprehensive analysis of the history of self starvation, see Vandereycken W & van Deth R From Fasting Saints to Anorexic Girls. London: Athelone Press, 1994.

Although, as Giordana (supra, n23) points out, the moral values associated with lightness may be an important motivation. Susie Orbach (supra, n40) also explores the links between thinness, self-denial and femininity. Marsden P. *et al.* ('Spirituality and clinical care in eating disorders: a qualitative study.' *Int J. Eat. Disord.* 2007; 40(1):7-12) highlight the importance of recognising the influence of the beliefs of strongly religious patients on clinical outcome.

⁹⁶ With respect to religious aspects of eating disorders, it is interesting that although I was raised as an atheist, when I was sick I did experience and articulate my illness in religious terms. I regarded my anorexia as a devil or succubus that possessed me, and considered eating, resting and weight gain as 'sinful'. This strongly influenced my reaction towards, and experience of, therapy.

means that whatever autonomy the anorexic exercises is to some extent limited.⁹⁷ The lifestyle anorexic thus meets conditions one, two and four that would justify the use of compulsion – she is treatment resistant, her health and welfare is endangered, and her autonomy is compromised. The use of coercion must also meet the requirements of beneficence and non-maleficence, however. Is such intervention in her best interests, or does it further undermine her autonomy?

3.4.4.3 Positive and negative autonomy

Regardless of whether we adopt a 'self governance' or 'social' definition, respecting an anorexic's *negative* autonomy (the right not to have her choices interfered with) prevents or even impairs the advancement of her *positive* autonomy (the ability to fully engage in what we consider a full and meaningful life). ⁹⁸ Criterion three states that potentially effective treatment must be available and not undermined by the use of compulsion, but it could be argued that *failing* to use compulsion undermines the potential efficacy of treatment. By *not* intervening, we are thus failing in our duties of both beneficence *and* non-maleficence. This is the argument from positive rights.

The longer a pattern of anorexic behaviour continues, the harder it is to change, lessening the person's ability to choose to accept treatment at some future point in time, and decreasing the probability of therapeutic success. Rather than learn alternative ways of handling stressful situations, for example, she may come to rely on inpatient treatment as a 'way out' when life gets too difficult. This produces a quandary for doctors who are charged with the care of lifestyle anorexics. What should a doctor do with a patient who has been admitted on medical grounds and who requests to remain in hospital for longer than necessary for basic physical stabilization? Consider the case of an identity anorexic who has been through repeated weight restoration programmes and freely admits that these periods provide her with a 'holiday' whereby she can eat and rest without guilt because the decision to do so is no longer her responsibility. She refuses all other psychological intervention, maintaining that she is unable to cope with giving up her identity, and loses all the weight

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⁹⁷ In 'Autonomy and Personal History' (*Can. J. Philos.* 1991; 21(1):1-24), John Christman proposes a theory of individual autonomy that focuses on the manner by which a person comes to have a set of desires, rather than Dworkin's analysis of her attitude *towards* those desires. At the point at which she develops the values and desires associated with anorexia, she was not in the position to resist them, and would thus also be considered non-autonomous by Christman's analysis.

⁹⁸ This is not, of course, an issue only for anorexic patients. There is a more general criticism that the overemphasis on (negative) rights leaves people to rot. See, for example, Jacobson PD. & Soliman S. 'Coopting the health and human rights movement.' *J. Law, Med and Ethics* 2002; 30(4):705-718; Mumentz et al. 'The Ethics of Mandatory Community Treatment.' *J. Am. Acad. Psychiatry Law* 2003; 31:173-183.

gained every time she is discharged. Permitting her to remain or discharging her *without* undertaking additional treatment will lead to physical deterioration, and further entrench her behaviour. Requiring her to take part in a wider therapeutic programme could thus be justified under soft paternalism because the short-term infringement of her negative autonomy (hopefully) serves to enhance her positive autonomy in the longer term. ⁹⁹

3.4.6 *Is coercion the only way to advance the identity anorexic's interests?*

Criterion three requires that treatment has the potential to be effective, but if there is a noncoercive way to benefit an anorexic patient that does not undermine her already compromised autonomy, we ought to use this instead. 'Recovery' is not the only way to break the social isolation that accompanies the anorexic life. Another would be to remove the label of 'mental illness'. Although partially self-imposed, social exclusion is also externally driven. Not only is there the stigma that accompanies the label 'mental illness,' the physical emaciation both scares and fascinates people. The anorexic is regarded with the same mixture of disgust and awe as an exhibit in a freak show rather than a person in her own right. 100 A common assumption is that it is a simple matter of *choosing* not to eat, and is either an exercise in vanity or attention-seeking behaviour rather than the solution to more complex issues. This adds further to the sense of shame many anorexics already feel, ¹⁰¹ and one result of the negative stereotyping is that anorexics create their own narratives in which their condition is a sign of strength and empowerment, adding to the value the condition already has for them. 102 It also means that anorexics create their own, exclusionary social networks (such as pro-ana web sites), not only as a source of support and empathy but also as a source of information on how to be anorexic or to become better anorexics. 103 By changing the public perception of anorexia and making it more acceptable (or at least understandable), this isolation will be, if not eliminated, at least weakened. A better understanding of the complexities underlying the condition would enhance the emotional support that friends and family can provide. It might also encourage those who have

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⁹⁹ This is entirely consistent with Millian autonomy. Mill considered paternalism justified if non-responsible individuals (a category in which he included the mentally ill) are about to harm their own ability to exercise their rights fully, and that intervention will enhance their ability for self-government or at least prevent further deterioration.

Although there is also a history of 'starving artists' who made their living in this way. See Vandereycken and van Deth, supra, n93 Chapter 5: 'Hunger Artists and Living Skeletons'; p74-96.

¹⁰¹ Skårderud F. 'Shame and Pride in Anorexia Nervosa: A Qualitative Descriptive Study.' *Eur. Eat. Disord. Rev.* 2007; 15:81-97.

For a more in-depth, interview-based discussion of this area see ibid; Rich 06, supra, n42.

¹⁰³ Ibid; Cipske & Horne 07, supra, n42.

recovered to be more open about their own experiences, acting as inspiration or role models to those who are themselves working towards health.

Although this is an argument against using the Mental Health Act as a means of compelling anorexics to accept treatment, the same effect could be achieved by making greater use of the PPPRA and adult guardianship orders, thus avoiding the stigmatic labelling.¹⁰⁴

Rebecca Dresser puts forward an alternative argument. 105 The increasing prevalence of eating disorders is often linked to media portrayals of size 0 models and an ideal of female beauty emphasizing thinness at the same time as we are bombarded with reports about the obesity epidemic and the need to lose weight and exercise. Excessive thinness is made glamorous in the fashion industry and on every magazine cover emblazoned with the latest anorexic starlet, creating the impression that anorexia can be adopted and discarded at will. 106 Such developments move what are 'classical' ethical issues around autonomy, responsibility and harm from the healthcare setting to the wider social arena. Dresser suggests that if we adopt a socio-cultural explanation for anorexia, compulsion should be used only in the most extreme cases, and the burden of dealing with the condition should then fall on other social institutions. She points out that if cultural forces cause anorexia, changing these will be more effective than coercing individual patients to accept treatment. Given, however, the increasing prevalence of anorexia and the 'infectious' nature of eating disorders, accepting anorexia as a valid way of life is likely to exacerbate rather than resolve current problems. In addition, social change is slow, and in the meantime clinicians have a duty towards individual patients as they arise.

As already discussed, there are grounds for considering that anorexia *does* compromise a person's autonomy, harms not only the anorexic but her friends and family (in whom she has other-regarding interests), and, potentially other susceptible members of society. All of these considerations must be balanced against the potential harm to the anorexic of being forced to accept treatment. Given the questionable status of a 'lifestyle' anorexic's autonomy, and the additional considerations of indirect harm to others of her behaviour, I conclude that criterion four is satisfied. Compulsory treatment can thus be justified under weak paternalism, provided there is effective therapy available.

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Provided the competency criteria recognise anorexic identity as impairing competency to refuse treatment.

Many people actually commented to me that they would like to catch a little of what I had!

3.5 Treatment

Although those seeking to 'cure' an anorexic patient are acting with her own best interests at heart, are good intentions sufficient moral justification for overriding the patient's own stated desires? While a large percentage of anorexics will recover, ¹⁰⁷ not all do, and it has been argued that such patients should be offered palliative care and allowed to refuse all medical intervention. Enforced treatment requires a patient to sacrifice her identity (and the benefits that it provides) with no certainty that it will be replaced with one that she regards as better. Repeated fluctuations in weight are more detrimental to health than a constant, if low, body mass index (BMI). 108 Because there is general agreement that successful treatment requires voluntary participation, it seems on the face of it that some anorexics will not benefit from compulsory treatment, and it may have negative long-term consequences. 109 Does compulsory treatment for anorexia work, and is effective treatment available in New Zealand?

3.5.1 Treatment Efficacy

If weak paternalism is to be justified and the criteria mentioned earlier are to be met, coercive treatment needs to benefit the patient. Whether the use of compulsion is effective in treating anorexia is contentious, however. At one extreme it is argued that enforced treatment (at least for severe anorexia) is both clinically and ethically appropriate, or is necessary to allow other therapies to be effective. Others contend that coercion is always a clinical mistake because eating disorders are an external expression of an internal need for autonomy and control, and enforced intervention will be counter-productive. 110

There are several reasons why doctors are reluctant to compel anorexics into treatment. Firstly there is the power imbalance that exists between clinician and patient, which puts the already limited autonomy of the anorexic at further risk. Although this is a very real and genuine concern, the loss of independence on the behalf of the patient can be balanced by the formation of a trusting relationship with her treatment team. It is here that an understanding of the importance of the illness to the patient would seem to be especially important, since the anorexic behaviour meets very real needs for her. If she is to let go of

 $^{^{107}}$ 50-75% over the course of 10 years according to a 1995 report by Eckert $\it et~al.$ '10 Year Follow –up of Anorexia Nervosa: Clinical course and Outcome.' Psychological Medicine 1995; 25:143-156.

¹⁰⁸ Morris & Twaddle 07, supra, n24.

Gowers SG. et al. 'Impact of hospitilisation on the outcome of adolescent anorexia nervosa.' Br. J. Psychiatry 2000; 176:138-141; Ben-Tovim DI. et al. 'Outcome in patients with eating disorders: A 5-year study.' Lancet 2001; 357:1254-1257.

For a more in-depth discussion see Giordana, supra, n23 p200-205.

her anorexic identity, she has to trust that those needs are acknowledged and that she will be able to find new (and hopefully less harmful) ways of fulfilling those needs. Nor is this a permanent state of dependence, but a step towards enabling her emotionally, physically and psychologically. As treatment progresses, she will regain autonomy as well as weight (a process that could be seen metaphorically as second adolescence). Rather than limit her choices, the aim of treatment is to expand the possibilities open to her—including the option to return to anorexia if she so chooses.

A second concern is that compulsion is counterproductive, making the patient non-compliant (or only superficially compliant) and only serves to damage the therapeutic relationship. Studies have shown, however, that this is not necessarily the case if is explained that it is done not as punishment but out of genuine care and concern. A recent review of the available evidence concluded (among other things) that:

- Coercion should not be used instead of psychotherapy, nor does the former preclude the latter.
- Applications for guardianship should allow for the possibility of 3-6 months detention.
- Mortality increases when BMI falls below 13, and this should be considered a threshold for compulsion.
- Compulsory treatment should be used sparingly and for as short a time as possible. Interpersonal and psychotherapeutic relationships are more important than force.
- Coercion in *feeding* should be minimised, and patients encouraged to eat independently.
- Feeding and weight should not be emphasised. The main aim is the voluntary continuation of treatment.¹¹³

Empirical research on the efficacy of compulsory treatment is limited and is complicated by the fact that coercion is often used on more severely ill (and often chronic) patients or those with comorbid diagnoses. Although one study found a higher mortality rate among

Carney T. et al. 'Why (and When) Clinicians Compel Treatment of Anorexia Nervosa Patients.' Eur. J. Eat. Disord. Rev. 2008; 16:199-206; Carney 09, supra, n6.

Bruch H. 'Perils of behaviour modification in treatment of anorexia nervosa.' *JAMA* 1974; 230:1419-1422.
 Saferty M & McClusky S. 'Compulsory Treatment of Anorexia Nervosa and the Moribund Patient.' *Eur. Eat. Disord. Rev.* 1998; 6:27-37.

Theil A. & Paul T. 'Compulsory treatment in anorexia nervosa.' *Psychother. Psychosom. Med. Psychol.* 2007: 57:128-135

involuntary patients several years after treatment, this probably reflects the fact that compulsory patients had a longer and more intractable history than voluntary patients, ¹¹⁵ and several studies have found that voluntary and involuntary patients have similar short-term outcomes. ¹¹⁶ Some of these differences may reflect the severity of the patients, and/or the type of treatment (force feeding, behavioural modification etc) involved. There is some evidence that intensive nursing approaches can be successful if used appropriately. ¹¹⁷

Post-hoc ethical and clinical justification is also provided by the fact that in one study up to 50% of involuntary patients later acknowledged that it was necessary and/or beneficial. In fact there is even evidence that initial coercion may be necessary to allow an anorexic to engage in further treatment, and that their attitude towards perceived coercion changes over the course of treatment, and they come to recognize that intervention was necessary. 119

3.5.2 Availability

Treatment must not only be effective, but also available, if it is to benefit patients and thus be acceptable under weak paternalism. Compelling patients to accept treatments in an environment where the effectiveness of coercion is undermined, 120 is not ethically justified, even if this is a temporary measure used only until a bed becomes available in a specialist unit. One of the biggest considerations in changing the law in such a way as to increase the number of anorexics potentially subject to compulsory treatment is thus whether current inpatient services can cope. Effective programmes are expensive, lengthy and labour intensive, combining weight restoration with a range of other therapies involving both the patient and her family. Anecdotal evidence gleaned from news reports and discussions with those working with anorexic patients point to a severe shortage of beds in all four main centres. Some programmes (such as the Christchurch service) will only accept voluntary

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¹¹⁵ Ramsay R. *et al.* 'Compulsory treatment in anorexia nervosa: short-term benefits and long-term mortality.' *Br. J. Psychiatry* 1999; 175:147-153.

¹¹⁶ Ben-Tovim 01, supra, n109.

Thiels C. 'Forced treatment of patients with anorexia.' Curr. Opin. Psychiatry 2008; 21:495-498.

Guarda 07, supra, n27. This was also my own experience. By being *made* to eat, I was spared the overwhelming guilt and punishment my 'anorexic self' inflicted on me, and I turned my anger outward rather than inward (for which I later apologised).

Watson TL. et al.' Involuntary Treatment of Eating Disorders.' Am. J. Psychiatry 2000; 157:1806-1810; Guarda 07, supra, n27. In Re Jane (District Court, Auckland, 16; 30 September 1988) is a case in point; Judge McElrae authorised treatment while he established whether anorexia was a mental illness. By the time he decided it was, she had reached 42.5kg and remained as a voluntary patient.

¹²⁰ For example, anorexics detained in general mental health wards will often compete to get sicker rather than support each other's recovery.

patients and have waiting lists of 6 months or more, while other patients are sent (or opt for) treatment overseas. Detention *without* treatment, or the provision of inappropriate treatment, can worsen a patient's condition and make subsequent recovery more difficult (this was certainly my experience). Although legislative changes may highlight the need to increase funding in this area, this service bottleneck is unlikely to be addressed in the short term. The availability of effective treatment therefore needs to be an important consideration in determining whether the use of compulsion is justified.

CHAPTER FOUR: COMPULSORY TREATMENT UNDER THE PROTECTION OF PERSONAL AND PROPERTY RIGHTS ACT 1988.

Although the PPPRA has rarely been used to authorise compulsory treatment of an anorexic patient, ¹²¹ a number of international jurisdictions use adult guardianship rather than mental health legislation for anorexic patients. There are several arguments advanced in favour of this approach. It may be less obtrusive than the MHA, and by respecting patient autonomy may be less damaging to the therapeutic relationship. It also provides a check on the power of clinicians, and avoids the stigma associated with mental health processes. On the other hand, the requirement for competent consent can pose a problem for clinicians because of the ambivalence towards treatment that many anorexics display (for example, they may agree to treatment when they are at a particularly low ebb physically, only to withdraw that consent as soon as it becomes clear that it is effective). This either makes consent meaningless, or leads to clinicians declining to intervene until a 'greater clarity is obtained'. ¹²²

4.1 Structure of the PPPRA

4.1.1 Jurisdiction

The rights-based focus of the PPPRA is evident from its full title, "An Act to provide for the protection and promotion of the personal and property rights of persons who are not fully able to manage their own affairs." While recognising that substitute decision-making may be necessary when a person is incapacitated by injury, illness or disability, ¹²³ the PPPRA is intended to clearly delineate the areas in which intervention is (and is not) permitted, and to hold those carrying proxy consent-powers to account. The primary objectives of the Act are spelt out explicitly in section 8: to "make the least restrictive intervention possible" and "to enable or encourage the person to exercise and develop their capacities to the greatest extent possible." The Family Court has also been described as the "bulwark of the protection of individuals in respect of whom applications are made." The potentially broad jurisdiction

 $^{^{121}}$ Re CMC [1995] NZFLR 538, also called Re C [1995] FRNZ 112.

¹²² Carney 03, supra, n7.

The Act has been invoked for conditions ranging from stroke, head injury and dementia to psychiatric disorders and intellectual disability.

¹²⁴ In the Matter of A [1996] NZFLR 359 (also known as Re A, B and C [1996] 2 NZLR 354) at 366; Re NH (1997) NZFLR 92 at 95.

of the Court is curtailed by the presumption of competence and the focus on the decision-making process (functional competence) rather than the content of the final decision. Before issuing an order with respect to a person, the Court must first be satisfied that the person lacks the capacity (wholly or partially) to understand the nature of the options available to her, is unable to foresee the consequences to her health and welfare of her decisions, or cannot communicate the content of a competent choice. The fact that a person's decision appears unreasonable or imprudent is not *in itself* sufficient proof of incapacity. It must also be established that there is no other way the difficulties can be resolved (by providing additional assistance or presenting information in more accessible language, for example), and what is authorized will depend upon the nature, context and urgency of the decisions to be made. 127

4.1.2 Types of Order

Having established that a person lacks the necessary capacity and that judicial involvement is necessary, the Court has two options by which compulsory treatment can be authorised; a personal order specifying the type and duration of intervention to be undertaken, ¹²⁸ or the appointment of a welfare guardian to make decisions on the patient's behalf. ¹²⁹ Personal orders are preferred over welfare guardianship on the basis that the former are less restrictive (requiring review after 1 year if no date for expiry is specified), but they can be used to place considerable restrictions on a patient. ¹³⁰ While it has been suggested that the use of treatment and guardianship orders grant too little authority to clinicians, or creates intra-familial conflict if a family member is appointed guardian, ¹³¹ a judge could potentially

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¹²⁵ PPPRA 1988 s6

¹²⁶ See, for example, the views of Dr Tapsell on Mr R in *Re L* [2001] NZFLR 310 at 31.

[&]quot;Under the benign [PPPRA] 1988 the power of the Family Court to exercise its protective jurisdiction by intervening in a person's life and affairs depends on whether that person's capacity or competence is shown to be sufficiently limited. It also depends on the extent to which that intervention is shown to be necessary:" Inglis J. in *Re Tony* [1990] NZFLR 609.

¹²⁸ PPPRA s10

¹²⁹ PPPRA s12

These have included sterilisation, force-feeding, electroconvulsive therapy, the use of seclusion or restraint, or the requirement for Court authorisation for changes in living arrangements. See, for example *Re H* [1993] NZFLR 225; *R v R* [2004] NZFLR 797 (also known as *KR v MR* [2004] 2 NZLR 847); *R v R* (No 2) [2004] NZFLR 817; *Re CMC, supra*, n120; *In the matter of IMT* [1994] NZFLR 612; *In the Matter of A, supra*, n124.

These concerns have been raised in both Israel and Japan, where guardianship orders are used to initiate involuntary treatment for anorexia.

order a patient to accept whatever treatment her doctors consider in her best interests, or grant guardianship authority to a clinician rather than a family member. ¹³²

4.1.3 Competence

Philosophically, the right to refuse treatment derives from the principle of autonomy. Competence is both a means of determining whether a person is making a free choice, and a prerequisite for autonomy; individuals who lack competence or decision-making capacity are not acting in a fully autonomous manner when they make decisions, ¹³³ and we are justified in intervening to protect their welfare.

Like autonomy, there are different ways in which competence is defined, depending on social and cultural values. As discussed earlier, the Western world adopts a Millian definition of autonomy as self-determination; a freely made decision is valuable regardless of its content or consequences, and ought to be respected. This is reflected in how competence is understood. In a legal sense, competence is usually described as a person's capacity to perform a task at the level at which it ought to be performed (as determined by some normative standard). Under New Zealand law, the criteria for assessing competence in decision-making are largely procedural, depending on the ability to:

- 1. Understand and retain the information relevant to the question at hand;
- 2. Believe that information; and
- 3. Weigh the information in the balance to arrive at a choice.
- 4. Communicate a settled choice. 134

People's ability to make choices will depend on both the nature of the decision and the context in which it is made. 135 If, for example, a patient's thinking is impaired by medication or pain, or she is intimidated by being asked to make choices in an unfamiliar hospital setting, her ability to understand or weigh the information provided to her would be impaired, compromising her competence to make medical decisions.

 $^{^{132}}$ A variation of this has been used with moderate success in other jurisdictions. For example in the NSW case DoCS v Y [1999] NSWSC 664, a 16 year old anorexic patient was made a ward of the court and a senior clinician appointed to oversee and co-ordinate her treatment.

¹³³ Kennedy I. & Grubb A. in Medical Law-Texts and Materials (Second edition). London: Butterworths,

¹³⁴ Re FT (District Court, Auckland PPPR 68/94, 11 January 1995); In the Matter of G [1994] NZFLR 445. These criteria are very similar to the clinical MacCAT competence test.

Buchanan AE. & Brock D. In Deciding for Others: The Ethics of Surrogate Decision Making. New York: Cambridge University Press, 1989; Chapter 1: 'Competence and incompetence'; p19-29.

The degree of competence required for any particular decision will also depend upon the consequences that will flow from that choice. The more serious the consequences of a decision are, the higher the threshold for competence becomes. Because physicians are presumed to be acting in the best interests of their patients (and have a greater degree of knowledge about the likely outcomes), competence tends to be more readily assumed when a person accepts treatment than when they reject it. Similarly, courts have tended to adopt an approach whereby a greater degree of understanding is required for rejection of therapy than for acceptance (an asymmetry that arises because the risk of serious consequences or even death raise the bar for treatment refusal). In the widely cited British case *Re T*, the Court of Appeal expressed the opinion that, even though T's refusal of a blood transfusion was competent, she did not at the time anticipate that her condition would become life-threatening, and was thus non-binding in the emergency situation that subsequently developed. Lord Donaldson further declared that even if her refusal *had* covered that eventuality, she was so physically and emotionally weak that her mother (who was a devout Jehovah's Witness) held undue influence over her decision. 138

4.1.4 Treatment Futility

Regardless of competence, there are certainly cases where compulsion is not in the patient's best interests. As discussed in Chapter 3, an additional consideration is the level of suffering that intervention causes for the patient. Although the PPPRA is framed in the language of rights rather than welfare, competence is important because a person's best interests are served by respecting their autonomy. Even though not explicitly mentioned in the statute, the law has been interpreted in relation to personal welfare. This means that even if the patient is found incompetent, if intervention is likely to be of no benefit an application for a treatment order under the PPPRA would be refused.

4.1.5 Release from the PPPRA

A review of a personal or guardianship order can be requested at any time by the patient, her guardian, or any person authorised by the Court, at which point the patient's capacity is

 $^{^{136}}$ Richardson G. 'Autonomy, guardianship and mental disorder: One problem, two solutions.' *Modern Law Review* 2002; 65:702-723.

¹³⁷ [1992] 3 WLR 782.

¹³⁸ Ihid at 22

Under Section 8, intervention must be the least restrictive possible, proportional to the degree of incompetence, and intended to develop the person's capacity for decision-making.

evaluated using the same criteria as originally used to determine jurisdiction. ¹⁴⁰ In other words, if, she is found to be competent at the time of the review, she should be released from the order. Regaining the capacity to make treatment decisions does not automatically lead to discharge from the Act, however. Fluctuating cognitive ability may be taken as evidence of partial incapacity, 141 and re-engagement with the Court process is required if the order is to be lifted before the specified date (unlike the Mental Health Act where a psychiatrist must release a patient when they cease to be mentally disordered). ¹⁴² Automatic reviews are also less frequent under the PPPRA than under the MHA, with the first often being 1 year after the initial order, while a second order can be given for up to 3 years. 143

4.2 Anorexia and competence

Courts seem to have accepted that anorexics are (in general) able to understand and retain information regarding their care, but lack the ability to appreciate the significance of the facts (ie, that it will lead to serious physical harm or even death). Often this will be manifest in contradictory desires, for example, wishing to live and simultaneously refusing to take in life-sustaining sustenance. In some situations, disordered thinking or lack of understanding impairs competence. In FAH, for example, the patient argued that she was being deprived of the right to choose whether to live or die, but failed to understand how seriously endangered she was. 144 Similarly, in Re CMC, 145 the first (and only) anorexic patient in New Zealand to be compulsorily treated under the PPPRA, the patient's inability to consider the question of treatment logically was obvious. Despite wanting to live and recover, she was unable to put on weight voluntarily because her food choices were so selective she was unable to eat a full and balanced diet, and the fear of weight gain so overwhelming that she refused nasogastric feeding as soon as it became clear that this was effective. As Judge MacCormick observed:

¹⁴⁰ PPPRA s86(1), (2), (4).

Although the focus of the PPPRA is on the competence of a person's decisions at the time rather than at some point in the future, fluctuations in capacity may also bring a person under the jurisdiction of the PPPRA. In Re L (supra, n126) an elderly woman who suffered from periodic episodes of psychosis (but was competent at other times) was found to be partly lacking capacity within the meaning of s6 because the judge considered that a longitudinal consideration of the evidence was appropriate, a common sense approach. This precedent could potentially be used to authorise ongoing treatment for an anorexic patient whose competence returns as her weight increases, particularly if she has a history of repeated weight loss after compulsion is removed.

Although mental disorder may be intermittent rather than continuous under the Act.

This raises the possibility that for those with limited external support, it may actually be *more* difficult for a patient to be released from compulsory treatment under the PPPRA than the MHA. The MHA requires two 6monthly reviews of patient status before an order is made indefinite, and the patient's psychiatrist is still legally required to release a compulsory patient at any point if they no longer consider them mentally disordered. ¹⁴⁴ Re FAH, (SRT 29/98, 18 May 1999; NZFLR 615).

¹⁴⁵ Supra, n121.

Whilst she stated that she wished to survive and wished to have a future quality relationship with her children - indeed, wished to attain an optimum weight for her own wellbeing, she could not see what was necessary in order for this to be achieved.

There is little dispute that an anorexic is incapable of making reasoned decisions in specific contexts. There is good clinical evidence that procedural autonomy (the ability to understand the consequences of one's choice of action, and to balance the costs and benefits of alternative choices) is impaired with relation to issues of food, and weight. Cognitive studies have shown that an anorexic's information processing with regard to eating-disordered behaviour is highly dysfunctional. An anorexic will commonly interpret comments such as "you are looking better" as "you are getting fat", and have detailed knowledge of nutrition but will remain unable to apply it to herself (so rather than eating a diet which will maintain her physical health, she will use this information to justify her food restrictions). In addition, her perception of appetite and satiety is distorted, and her competence to make reasoned and informed decisions about medical intervention may be compromised because of irrational fears (for example, of getting fat, losing control of her life) or an inability to comprehend the consequences of her actions.

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Some courts have claimed that treatment refusal is an inherent feature of anorexia and *a-priori* cannot be regarded as an informed choice, ¹⁴⁷ but such local incompetence does not necessarily mean an anorexic is incapable of making informed choices about other areas of her life. Many anorexics have a very clear understanding of their condition, and of both the difficulties of living with it and the risks involved. Their decisions regarding treatment may be based on deeply held values and preferences, and involve more than just balancing the physical costs and benefits. Other people's 'cure' may even mean relinquishing who and what they are.¹⁴⁸

¹⁴⁶ Giordana, supra, n31.

¹⁴⁷In *Re W*, Lord Donaldson opined: "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. This attitude is part and parcel of the disease and the more advanced the illness, the more compelling it may become." [1993] Fam 64 (UK). A similar view was expressed in *Re CMC* (supra, n121), where Judge MacCormick considered that Mrs C's inability to make informed decisions about the need for weight gain was a feature of her illness.

Patients may also accept the need for weight gain but disagree with clinicians about the *effectiveness* of treatment, as evidenced *In the Matter of CT* (MHRT No 07/116, 28 September 2007).

4.2.1 The PPPRA and end-stage anorexia

For a person who has been ill for many years, and for whom repeated treatments have been unsuccessful, a desire to die rather than continue to live in an intolerable situation is, at the very least, understandable. Both Heather Draper and Rebecca Dresser have argued that a chronic anorexic could competently refuse treatment because of her poor quality of life, in the same way that a cancer patient might refuse chemotherapy even if it might extend her life because the side effects rob her of enjoyment of the additional time she gains. ¹⁴⁹ In *Re CMC*, the Judge remarked that:

Had Mrs C not expressed a will to live, to recover fully and lead a future life with her family and in particular her children, then in exercising the ultimate discretion it might perhaps have been appropriate to decline to make the order. ¹⁵⁰

This suggests that a chronic anorexic might be considered competent to refuse life-sustaining treatment under the PPPRA. Even if the *reason* she finds weight gain is unbearable is rooted in the illness, ¹⁵¹ her decision could be regarded as legally competent if it is not focused on whether she needs to eat, but whether to continue living with anorexia. If she considers her current situation so poor that she derives no benefit from it, and the burden of therapy (and its consequences) too much to bear, it may be considered a quality-of-life decision similar to that made by many other medical patients.

In order to be considered competent, she would have to make this refusal at a stage where her cognitive ability is not compromised by her physical state (such as after a period of involuntary treatment). The court would need to be convinced that she understands that this refusal is likely to lead to her death, that this is what she really wants, and that she has been consistent in communicating this desire. Her decision would need to be based not on pathological values, such as preferring death to gaining weight, but on a realistic assessment of both her current quality of life and the low probability of any therapy succeeding. 152

Although, as Jo Oliver discusses in her analysis of this case, courts have been reluctant to allow competent patients to die when a low risk treatment is available. See 'Anorexia and the Refusal of Medical Treatment.' *VUWLR* 1997; 27:620-647.

¹⁴⁹ In essence, starving to death relieves her of both the burden of the disease and the burden of treatment.

This has been described as the 'anorexic paradox', whereby 'gaining weight' means inducing unbearable feelings that lead to a wish to die. Gans M. & Gunn W. 'End stage anorexia: Criteria for competence to refuse treatment.' *Int. J. Law Psychiatry* 2003; 26:677-697.

Because this is, to all intents and purposes, a request to be allowed to commit suicide, the court would probably require clinical confirmation treatment is futile, and consider disagreement between the patient and

Such a decision on the part of the patient would meet the competency requirements of the PPPRA, and is advocated by both Heather Draper and Rebecca Dresser.

Neither Draper nor Dresser claims that *every* competent anorexic ought to be allowed to refuse life saving treatment, however. It could be argued, for example, that an anorexic's ability to make a reasoned decision is compromised because her mental state overrides her ability to achieve the 'vital goal' of survival.¹⁵³ Heather Draper provides an arbitrary set of conditions that describe when treatment can be considered futile, which has already been argued to be insufficiently flexible. Rebecca Dresser suggests that the state's interests in discouraging suicide mean that there must be some method of ensuring this choice is well considered and consistent with the patient's general values and preferences. Although she suggests two general approaches, she provides no specific method for determining when this refusal should be honoured.¹⁵⁴

Another criticism of the approaches suggested by both Draper and Dresser is their sole focus on the patient. Although self-determination is important, end-of-life decisions have profound implications for others, particularly family, that the patient may not have fully considered. Because the consequences of such decisions are irrevocable, and death is entirely preventable, the analogy between a cancer patient and a chronic anorexic is not an exact one, and the consequences for the family, in particular, likely to be considerable. The current PPPRA does not expressly require the family's interests to be taken into account, but the patient's emotional as well as an intellectual understanding of the consequences of her decision, the impact on family, and whether all treatment options have been exhausted, should all be considered. A broader legal assessment of competence, both procedural and psychological, has been suggested by Margery Gans and William Gunn. Using an American case study, they outline a template for assessing cognitive and emotional competence in end-stage anorexia:

1. Cognitive:

• Can the patient understand and appreciate the meaning of death?

her doctor to be a sign she did not have a realistic view of her situation. If a patient has exhausted all available treatment options over the years without success, this could provide reasonable evidence further intervention is unlikely to succeed, even if clinicians disagree.

Beaumont P. & Carney T. 'Conceptual issues in theorising anorexia nervosa: Mere matters of semantics?' *Int. J. Law Psychiatry* 2003; 26:585-598.

The law could specify an anorexic must meet certain criteria (duration of illness, number of previous treatments etc), or require involuntarily treatment for a limited time to allow the patient to reconsider her choice in consultation with clinicians and recovered anorexics. Ironically, this latter approach would force compulsory treatment on a competent patient, a position Dresser argues against elsewhere in her article.

155 Supra n151.

- How do others (family and treatment team) assess the patient's cognitive ability and capacity to refuse treatment?
- Does she understand and appreciate the imminence and probability of death?
- Could she discuss the decision to refuse life support?
- What do family and treatment team think about the patient's ability to understand and appreciate her decision and its consequences?
- How aware is she of the effects of her anorexia on herself and her family?

2 Emotional:

- Can the patient appreciate the effects of her death on her family?
- Do her family's views on her death confirm or disaffirm her understanding?
- Does she have the ability to say goodbye to her family?
- Can she articulate her reasons for wanting to die?
- Can she and her family participate in a family meeting dealing with these issues?

Although the patient in question would have satisfied Draper's cognitive notion of competence, 156 the hospital ethics committee raised questions about her emotional competence. Assistance was provided to ensure that the emotional criteria were also met before her refusal of treatment was accepted. The advantage of this approach is that it takes into consideration both the patient's desires and the effect that her decision will have on those close to her. It also ensures her family are psychologically and emotionally prepared for her death, and is consistent with the relationship-based ethical framework outlined earlier. 157 A similar approach could be adopted in New Zealand, possibly in relation to the legal recognition of an advance directive.

 $^{^{156}}$ Other significant factors included the fact her illness had continued for 25 years without remission, leaving her with significant and irreversible medical complications. She had been through multiple treatments, which she had resisted, and her desire to refuse treatment had been consistent over time. She, her family and treatment team attested to her poor quality of life, and her mental status was adequate at the time of the

¹⁵⁷ The involvement of the family in the decision-making process was an important consideration in the case study discussed, and may not be applicable to all cases. Involving those close to the patient is important to provide insight into the patient's situation and ability to make choices, however. It also ensures that she is aware of the consequences of her decision for others and so can factor this into her decision. Where there is no immediate family or close friends, greater involvement by the treatment team might be appropriate.

4.2.2 The PPPRA and identity anorexia

Somebody who has come to consider anorexia as an integral part of her identity could potentially be described as being procedurally competent. She might function well in some aspects of her life, and acknowledge the risks associated with her weight and the difficulties associated with her anorexia. Refusing treatment because of a fear of getting fat or through denial of her illness might not seem to be the result of reasoned deliberation. Might she not, however, legitimately decide that the benefits she gains from remaining anorexic (a sense of security, self esteem etc) outweigh the physical and emotional costs of 'recovery'? She may be acting in accordance with her own personal values (analogous to the value some religions place on asceticism and physical self-denial), ¹⁵⁸ or have found that aspects of her anorexia assist her in other aspects of her life (for example, the self-control she exercises over eating might also extend to her work and career prospects). ¹⁵⁹ Alternatively, she may regard her 'illness' as an aspect of her identity, meaning that a decision to accept treatment requires balancing more than just physical risks and benefits. The fact that she gives different weight to some factors than other people might may make her (apparently) irrational, but not legally incompetent. ¹⁶⁰ This is spelt out explicitly in section 6(3) of the PPPRA:

The fact that a person in respect of whom the application is made for the exercise of the Court's jurisdiction has made or is intending to make any decision that a person exercising ordinary prudence would not have made or would not have made given the same circumstances is not *in itself* sufficient ground for the exercise of that jurisdiction by the court. (Italics mine).

Could such a patient then refuse any psychological therapy or restoration to 'normal' weight, provided she accepts that hospitalisation might be necessary if her physical condition becomes severely compromised?¹⁶¹ This is the position adopted by Rebecca Dresser, who argues that compulsory intervention should be limited to life-preserving

¹⁵⁸ For a discussion of the moral dimension of lightness, see Giordana, supra n23, Chapter 6: 'The Value of Lightness'; p109-131.

¹⁵⁹ Tan 03b, supra, n42.

Although this could also be interpreted as evidence that her decision-making processes have been overwhelmed by her illness. Beaumont & Carney 03, supra, n153.

Although 2% of anorexics surveyed by Norbø *et al.* ('The Meaning of Self-Starvation: Qualitative Study of Patients' Perception of Anorexia Nervosa.' *Int. J. Eat. Disord. Rev.* 2006; 39:556-564) saw anorexia as a means of dying, this would be considered suicide and thus morally impermissible in our current social climate. For the remaining 98%, the achievement of death was not one of their stated intentions.

treatment only. 162 This would make anorexia analogous to chronic physical illness that requires occasional management rather than a mental disorder to be recovered from, and remove much of the associated stigma. Although it might be objected that, unlike a chronic disease, anorexia *can* be cured, to enforce treatment would infringe the anorexic's right to live in accordance with principles she considers important. It is easy to imagine a patient with kidney disease choosing to stay on regular dialysis rather than undergoing a transplant because the mixing of two people's flesh in one body is sacrilegious, and there seems little difficulty in accepting this as a valid reason to reject a particular course of treatment.

If we accept that an anorexic can competently refuse life-preserving interventions, then there is no reason to assume that she cannot competently refuse other treatments, particularly because there are fewer justifications (such as the impact of her death on her family, or the state's interest in preventing suicide) for overriding her decision.

A qualitative, interview-based study of anorexic patients and their parents by Tan et al^{163} found that they experienced altered and unusual values towards weight and thinness that superseded other aspects of their lives and, in some cases, they experienced integration of anorexia into personal identity. Despite the fact that their concentration, beliefs and thought processes were altered in complex and varied ways, they still performed well in standard legal competency tests. Let me return to my own experience:

Although every day was a struggle both mentally and physically, I had yardsticks against which to measure myself. Although I had to constantly struggle to contain my appetites (physical and emotional), I knew I had the strength and ability to do so. It gave me a face to present to the world, so that nobody would be able to guess that inside I was greedy, lazy and selfish. For the first time in my life I had a peer group, and everybody who looked at me could tell I was an Anorexic, an identity that elicited attention, concern and even admiration. It was a ready-made excuse for failing to meet expectations (after all I was sick, so whatever I did accomplish was celebrated, and if I was unable to do something it was excused because of my illness). It also meant I was able to isolate myself emotionally and socially. By deliberately placing myself outside 'normal' society, I didn't have to risk being rejected because of aspects of who I was that were beyond my control. After 12 years

¹⁶³ 'Competence to Make Treatment Decisions in Anorexia Nervosa: Thinking Processes and Values.' *PPP* 2006: 13(4):267-282.

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¹⁶² This would apply to both competent and incompetent patients alike because she considers coercion counter-therapeutic.

of illness, I had no memory of what life was like before anorexia, other than the fact that I had always been an outsider for reasons I didn't understand. Giving up anorexia would have meant risking all of this, with no guarantee that I would be acceptable to others or myself. In fact, given the evidence, I could assume that I wouldn't be. If I relinquished my rigid self-discipline, all my Anorexic peers would know and judge me for my weakness and betrayal of the 'sisterhood'. If I were a normal weight, people would look at me and think I was fine, even though I still struggled constantly with day-to-day life. If I gave in to my desire to eat, to rest, these desires I had resisted for so long might come to completely overwhelm me, and I might become exactly the kind of person I had fought against for so long. Gaining weight, changing my behaviour quite literally meant abandoning a familiar self for an unknown (and potentially worse) identity. In other words, 'cure' represented an existential crisis.

Would my reasoning pass the legal competency test under the PPPRA? Based on the current criteria, it might.

- I understood that remaining as I was put my life and health at risk.
- I believed that information, and freely admitted to my illness and its potential consequences.
- I considered the hardships of my current life, and balanced it against the advantages anorexia gave me. Although, in theory, treatment would provide me with other ways to meet those needs, there were no guarantees. I decided that I preferred to remain as I was, knowing those advantages would remain, rather than risk losing them.
- I was able to clearly articulate my preferences to the clinical team.

What such an analysis fails to take into account is the fact that I valued my thinness so highly that all other considerations became secondary to that. As discussed earlier, attaching such importance to weight and identity effectively cut me off socially and emotionally from any kind of meaningful relationship that most people consider necessary to be a fully realised, autonomous human being. In addition, that 'anorexic identity' I shared with my fellow anorexics was, in large part, derived from physiological and behavioural changes that developed as a consequence of starvation, or at a point when I was unable to control my thoughts and behaviours. They had become so entrenched that I was incapable of choosing to be 'otherwise' because this was an incomprehensible concept, yet

I understood and believed the consequences of refusing treatment, and recognised that others *did* recover.

Whether my decision is legally competent depends on whether the required level of comprehension is at an intellectual level (ie that recovery is a theoretical possibility) or at an emotional level (that it could apply to me).

The Act speaks of competence as the ability to understand the nature, foresee the consequences of decisions, ¹⁶⁴ but neither 'understanding' nor 'foresight' are defined. Under case law, the criteria adopted are understanding, belief, reasoning and communication. Whilst some courts have spoken of 'appreciation', implying the ability to apply knowledge to oneself is necessary, ¹⁶⁵ this is a tacit interpretation. How strictly the Court applies the belief criteria may depend on a number of factors, including the proposed patient's vulnerability, ¹⁶⁶ or whether greater emphasis is given to "rights" or "welfare." ¹⁶⁷

Given this uncertainty, making compulsory treatment orders for anorexic patients under the MHA rather than the PPPRA can be ethically justified. An alternative approach is to refine the legal definition of competence to better reflect our understanding of autonomy. This would have the advantage of aligning the two pieces of legislation and would allow for the possibility of including a competency test in the MHA, thus allaying the legitimate concerns that the current Act does not allow for mental health patients to competently refuse treatment for their mental disorder, and may permit disproportionate interventions by physicians.

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¹⁶⁴ PPPRA s5.

¹⁶⁵ See, for example *In The Matter of G*, supra, n134; *In the Matter of FT* (Auckland District Court PPPR.68/94, 11 Jan 1995), cited in *Re CMC*, supra, n121.

¹⁶⁶ In The Matter of G, Judge Inglis said: "...[A] person cannot make a true choice between options the nature and consequences of which that person's intellectual disability or mental disorder prevent her from comprehending and evaluating." In this case, however, the patient was intellectually impaired, in an assisted living situation, and considered unable to understand what living independently would require.

Compare, for example, the finding *In The Matter of A* (supra, n123) with *T-E v B* [2009] NZFLR 844. In the former the Judge held that: "[It is] unhelpful to adopt a narrow, legalistic approach to the Act where the welfare and best interests...were part of a hidden rather than a stated objective." In the latter, the High Court declared: "The Act was intended to have a "rights" based focus rather than a welfare focus."

CHAPTER FIVE: COMPULSORY TREATMENT UNDER THE MENTAL HEALTH (COMPULSORY ASSESSMENT AND TREATMENT) ACT 1992

The MHA authorises treatment for mental disorder regardless of patient competence, and uses a longitudinal and predictive definition of mental disorder. It assumes that sustained intervention may be necessary for recovery or maintenance of the patient's health, despite fluctuations in the patient's willingness to accept treatment or capacity to make decisions about her care. While it grants clinicians a broad mandate for treatment, it may stigmatise patients because of its association with mental illness, and by focusing on patient welfare (as determined by the treatment team), may override the patient's right to self-determination and undermine already fragile autonomy.

5.1 Structure of the Act

5.1.1 Jurisdiction

The purposes of the Mental Health (Compulsory Assessment and Treatment) Act 1992 Act are therapeutic rather than punitive, and its intentions are evident in its full title: "An act to redefine the circumstances in which persons may be subjected to compulsory psychiatric assessment and treatment, to define the rights of such persons and to provide better protection for those rights and generally to reform and consolidate the law related to the assessment and treatment of persons suffering from mental disorder." In other words, it aims to balance a person's rights not to be arbitrarily detained and the need to protect those who are unable to care for themselves or who would otherwise find themselves subject to the Criminal Justice system. In order to achieve this, the Act specifies the conditions under which compulsion may be used (when the person subject to the order suffers from a mental disorder to such an extent that they pose a serious danger to themselves or others), ¹⁶⁹ and the Tribunal must be satisfied that a treatment order is necessary. Although not explicitly

¹⁶⁸ Unlike the PPPRA, the MHA leaves the determination of *what* treatment is necessary to the clinicians, although this distinction may be less important since under the PPPRA a Judge could rule that doctors may decide what treatment is appropriate, or appoint a clinician as the patient's welfare guardian.

¹⁶⁹ MH(CAT) Act s2.

¹⁷⁰ MH(CAT) Act, s27(3).

stated in the statute, the expectation is that any intervention is the least intrusive; community treatment orders are favoured over inpatient treatment.¹⁷¹

Like the PPPRA, there is a requirement for regular review (in this case both clinical, and tribunal), the right of appeal, and time limits on the duration of orders. The Act does permit (under certain circumstances) the detention of a person for assessment and treatment for up to 1 month before the Family or District Court hears an application for a compulsory treatment order, however.

5.1.2. The meaning of 'mental disorder'.

Clinical and legal definitions of mental disorder are not necessarily equivalent. How (or whether) 'mental illness' is defined in legislation has significant implications for who can be subject to compulsory treatment. On the one hand, a narrow interpretation may ensure that the power of the court to impose treatment is (justifiably) constrained, but prevent intervention where compulsory treatment would seem to most people to be indicated. On the other hand, if 'mental illness' is left *undefined*, there is the danger of people being arbitrarily treated because of the way their illness is regarded by the medical (or legal) profession. For example, refusal of treatment could be regarded as symptomatic of the illness and thus sufficient grounds to override the patient's objections.¹⁷²

What constitutes a mental disorder for the purposes of the 1992 Mental Health Act is specifically defined in Section 2:

Mental disorder, in relation to any person, means an abnormal state of mind (whether of a continuous or an intermittent nature), characterised by delusions, or by disorders of mood or perception or volition or cognition, of such a degree that it-

- (a) Poses a serious danger to the health or safety of that person or of others; or
- (b) Seriously diminishes the capacity of that person to take care of himself or herself.

¹⁷¹ MH(CAT) Act, s28. This is also consistent with the UN principles for treatment of persons with mental illness that patients have the right to be treated in the least restrictive environment possible (Article 1, principle 9).

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&</sup>lt;sup>172</sup> For example, under the New Zealand Mental Health Act (1969) term 'mental illness' was generally interpreted as having its 'ordinary and natural meaning', and *In Re Jane* (supra, n119) Judge McElrea invoked the Act on the basis that the lay perception is that an anorexic does not have full control over herself.

As with many laws, however, the tension between providing a general legal framework and the need to allow flexibility of application in specific cases leads to ambiguous wording. Interpretation must encompass the intentions behind the legislation and its application in case law. The Act does not define 'delusion' or any of the other abnormal states of mind that constitute mental disorder. It has been argued for example that 'abnormal' should be judged subjectively (in comparison to a person's usual state of mind), ¹⁷³ an approach rejected by both Mental Health Review Tribunals and the Court in favour of "normality" as defined by comparison to the community in general. To do otherwise would allow people to argue that because their mental illness was normal *to them*, they fall outside the ambit of the MHA. Such an interpretation seems counter to the intention of the legislation. ¹⁷⁴

5.1.3 Severity

The determination that a person has an abnormal state of mind of the necessary sort is not, in itself, sufficient grounds to compel them to accept treatment: there must be good and sufficient reason for doing so. As with the definition of 'mental abnormality', the severity criteria are open to interpretation, particularly because 'danger' and 'self-care' are not defined in the Act.

What constitutes serious danger (or seriously diminished capacity for self care) is context specific, and may involve making a judgement in which emotional, psychological and physical harm may be considered.¹⁷⁵ In *Re PT*¹⁷⁶ Justice Walsh outlined the following principles:

- 1. When considering serious danger to health, both the physical and psychological health must be considered.
- 2. When determining whether the abnormal state of mind poses a serious danger to the health or safety of the patient, the following criteria should be taken into account:
 - (a) The nature and magnitude of actual harm to the patient
 - (b) The longitudinal history of relapse

Bell & Brookbanks warn that: "The fact that a person's behaviour is deviant, maladapted or non-conformist, does not necessarily mean that it is a product of any disturbance of mental functioning...[T]he inclusion [in the Act] of conditions with no specific psychiatric meaning has allowed idiosyncratic and pragmatic manipulation of the term, particularly where there is no real evidence of a mental illness but there are more pressing reasons to detain an individual, such as potential suicide or threatening behaviour" Psychiatry and the Law. Wellington: Brookers, 1996; p77-78, cited in *Re PT* (NMHRT No 601/98, 1 July 1998).

¹⁷⁴ Ibid; see also *Re H*, supra n130.

¹⁷⁵ See *Re RWD* (1994) 12 FRNZ 387.

¹⁷⁶ [2001] NZFLR 79; also known as *Re T* (at 16)

- (c) Whether such longitudinal history indicates impairment to the psychosocial functioning of the patient to the extent that the plateaus of wellness achieved after each relapse are of both shorter duration and lower functionality.
- (e) That such history indicates the pattern of deteriorating mental health
- (e) The long-term danger to the mental health of the patient is so posed.

A wide range of factors can influence dangerousness, including the patient's history and degree of insight, environmental and social factors such as the support of friends and family, and (in the case of danger to others) the vulnerability of potential victims. A greater degree of risk is necessary to justify intervention based only on risk to self (as opposed to risk to others), but the list of what might constitute danger is a broad one. The Mental Health Act guidelines suggest such indicators as failure to comply with life-supporting medicine (eg, insulin), self-neglect (such as inattention to cooking and subsequent risk of fire), and a tendency towards overspending while in manic state, producing serious financial problems. The definition of 'self-care' is similarly loose, ranging from personal hygiene to social integration, and has even been used to uphold a person's positive rights to enhanced quality of life.

5.1.4 Necessity

Having determined that a person is mentally ill under the definition of the Act, the court must decide whether treatment is necessary. The safety of the individual (and society) must be balanced against a person's right to liberty and to refuse treatment. Given that the purpose of the MHA is to safeguard the rights of patients, it is intended to be used as a therapeutic rather than a punitive instrument, and should not be invoked unless there is no

¹⁷⁷ For a full discussion of these indicia see *In the Matter on MMG* (MHRT/NR 568/98, 18 November 1998).

¹⁷⁸ <u>Guidelines to the Mental Health (Compulsory Assessment and Treatment) Act 1992</u>. Wellington: Ministry of Health, 1 April 2000.

¹⁷⁹ MHRT/NR 324/95, 14 June 1995.

¹⁸⁰ For example, in *Re EW* (Auckland District Court MH 226/93, 7 February 1996), the Judge considered treatment was necessary to ensure the maintenance of the patient's mental functioning at a level where she has a reasonable enjoyment of life.

¹⁸¹ MH(CAT) Act s27(3). It must be noted, however, that 'voluntary' compliance may be achieved by threatening to invoke the Act.

Everyone has the right not to be arbitrarily arrested or detained s 22, NZ Bill of Rights Act 1990.

¹⁸³ Ibid, s11.

other way to protect the welfare of the parties involved, and the patient cannot be persuaded to undergo voluntary treatment. 184

It is in accordance with the UN principles for the treatment of persons with a mental illness that patients have the right to be treated in the least restrictive environment possible. This is reflected in the preference for community over inpatient treatment orders. 186

Following The Court of Appeal decision in *Waitemata Health*, ¹⁸⁷ the Review Tribunal has drawn a distinction between the necessity test used when an application is made for the *imposition* of a treatment order under s 27, and an application for *release* under s 79. In the latter case, necessity is relevant only insofar as it is relevant to the degree of danger patients poses to the safety of themselves or others if the order lapses. ¹⁸⁸

5.1.5 Treatment

Part 5 of the MHA details circumstances in which treatment may be provided. During the first and second assessment periods and the first month of a compulsory order, the patient must accept *all* treatment for their mental disorder that the responsible clinician directs. Subsequent to this, the patient must have the treatment fully explained to her before it is administered. Although her consent is preferable, if she refuses (or is considered not competent to give informed consent), it can be authorised by a Tribunal-appointed psychiatrist if he or she considers it to be in the patient's best interests. What constitutes 'treatment' is not defined in the Act, but the guidelines to the Act note that it includes all remedies that health professionals have available to them to manage mental illness. Although the intrusion on individual rights that compulsion represents would suggest that the prospect of therapeutic success should significantly outweigh the detrimental effects of

 $^{^{184}}$ As Judge Boshier observed in $Re\ O$ (District Court, Whangarei MH No.7/93, 4 March 199): "This Act is an Act having interventionist consequences, and intervention should only occur to a patient as a last resort."

Principle 9 (1), UN Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care (1991).

¹⁸⁶ MH(CAT) Act s28(2).

¹⁸⁷ Waitemata Health v Attorney General [2001] NZFLR 1122; (2001) FRNZ 216.

¹⁸⁸ "This consideration is quite different from the necessity test contained in s27(3) of the Act...It makes good sense that the issue of necessity may be a relevant consideration to whether or not a patient is mentally disordered, because the issue of compliance with treatment may impact directly and persuasively on the issue of whether the second limb is satisfied." *In the Matter of PFB* (MHRT 05/124, 15 December 2005) paras 25-26

¹⁸⁹ MH(CAT) Act, s58, s59(1).

¹⁹⁰ Ibid, s59 (2)(b).

¹⁹¹ Supra, n178 at 20.1

losing autonomy and liberty, ¹⁹² there is no absolute requirement that therapy be effective (although questions of efficacy and availability will have a bearing on whether the court issues a compulsory treatment order). ¹⁹³

5.1.6 Release from the MHA

Initial treatment orders are for of 6 months, at which point an extension hearing (for a second 6 month period of detention) must be held. This may be followed by a third hearing, granting an indefinite detention order. Discharge may be granted at any of these hearings if the patient is found to no longer suffer from a mental disorder. In addition, there must be a clinical review 3 months after the initial compulsory treatment order is made, and subsequent reviews are required every 6 months. In addition to these statutory reviews, there is the option for review by the Mental Health Tribunal or the High Court.

Clinicians must discharge the patient from compulsory status if they consider the person is fit to be released, ¹⁹⁷ but the ruling of the Court of Appeal in *Waitemata Health* has found that a person could not be released from compulsory treatment as long as they remained 'mentally disordered in the statutory sense'.

5.2 Anorexia as a mental disorder

With respect to anorexia, some writers have suggested that eating disorders are not a medical or psychiatric condition, but are meaningful (and understandable) behaviours that meet specific needs. Given, however, the objective nature of the 'normality' test (and the absence of any need to establish the *cause* of the abnormal state of mind), the suggestion anorexic behaviours could be considered 'normal' have been rejected in the courts.

¹⁹² Bell & Brookbanks, supra n173 at p107. See also Simpson AIF. In <u>Involuntary Detention and Therapeutic Jurisprudence: International Perspectives on Civil Commitment.</u> Deisfeld K & Freckelton I (Eds). Aldershot: Ashgate, 2003; Chapter 20: 'A Clinical Perspective on Involuntary Outpatient Treatment: Efficacy and Ethics'; p469-484.

p469-484.

193 Issues of treatment options and efficacy in anorexia are comprehensively discussed in *Re FAH* (supra, n144) and *In the Matter of LKR* (SRT 40/2001, 22 August 2001).

¹⁹⁴ MH(CAT) Act s34.

¹⁹⁵ MH(CAT) Act s76(1), 77(1), 78(1).

¹⁹⁶ MH(CAT) Act s84.

¹⁹⁷ MH(CAT) Act s76(5).

Although a wide range of theories have been proposed to explain anorexia, most agree it is purposeful activity. This is supported by accounts of anorexics themselves. For a summary of the various cultural, purposive and identity-based conceptualisations of anorexia see Giordana, supra, n23; or Gillett 09, supra, n23.

See. for example *In the Matter of CT* (supra, n14).

If we accept that anorexic thinking is not 'normal', is it abnormal in the necessary way? Is an anorexic identity a mental disorder? On the face of it, the mental states that characterise an 'abnormal state of mind' (delusion, mood, volition, cognition, perception) would appear to restrict the ambit of the Act to those with recognised psychiatric illness, but a strictly 'diagnostic' approach has been specifically rejected by the courts in favour of a 'common language' interpretation of these terms. ²⁰⁰ In Re H, ²⁰¹Judge Inglis QC considered that a specific diagnosis, although relevant with respect to treatment, had no bearing on whether a person was mentally disordered for the purposes of the Act. 202 Subsequent judgments have endorsed the idea that classification of patient into one of these defined categories of mental abnormality is justified if treatment is in her best interests (or, in the case of those who pose a danger to others, in the interests of the community). This essentially reverses the nexus between the abnormal state of mind and its subsequent dangerousness. In cases where the causal connection is not clear (such as with personality disorder). Tribunals have determined firstly whether the patient meets the severity criteria of the 'mental disorder' definition and then considered this as symptomatic of an abnormal state of mind. 203

The definitive definition of "mental disorder" was provided by the Court of Appeal in *Waitemata Health*, ²⁰⁴ and further refined in *Re IM*:²⁰⁵

As the Court stated in <u>Waitemata Health</u>...the Act avoids reference mental or psychiatric illnesses. It is open to the Courts and Tribunals to regard

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Due, in part, because psychiatrists have proved unwilling to describe personality and behavioural disorders as meeting the clinical definitions of 'mental disorder', resulting in a broadening of these definitions that has implications for those suffering from other conditions (a situation I will discuss later).

^[1996] NZFLR 998 (at p1001).

202 "The expression mental disorder is used simply as a convenient term to describe a combination of threshold circumstances which must be found to exist in a particular patient before that patient can be required to undergo compulsory assessment and treatment:" Re H [1993] NZFLR 842, at p1001. See also Re Review Tribunal (RT), SRT 13/96,12 April 1996 at p 3: "The Act is not concerned with diagnostic labelling. Parliament has deliberately eschewed reference to particular mental disorders as understood and considered in the psychiatric community. Rather it has set the parameters for establishing the existence or otherwise of a mental disorder according to the presence or absence of observable symptomatic indices."

²⁰³ In cases such as SJE, IC and RCH, citing it as evidence that the first limb has been satisfied. This is eloquently summarised by the Tribunal in *Re PDG* (MHRT/NR No 465, 22 August 1997), which considered that:

[&]quot;[T]he exercise is not so much looking at the mental disorder definition and assessing whether the applicant fits within it, but looking first at the applicant and determining whether the applicant should fit within it."

²⁰⁴ "A recognised and severe (personality) disorder which has the phenomenological consequences identified in the definition of mental disorder...of the severity indicated in the definition...would in normal speech be an "abnormal state of mind." Supra, n187 p1141.

²⁰⁵ In the Matter of an Application by IM, MHRT 05/133, 16 February 2006.

behaviours as *amounting to* delusions or one of the four stated disorders, without those behaviours necessarily being capable of being so described in classical psychiatric terms...

- 1. The definition [of mental disorder] does not require that there be a causal connection between [the behaviours and] delusions or any one of the four disorders named;
- 2. It is the abnormal state of mind which must pose a serious danger or seriously diminish self care, in order that a finding of mental disorder may be made;
- 3. The definition states that mental disorder...means an abnormal state of mind...of such a degree that "it" poses a serious danger, the word "it" clearly referring to the abnormal state of mind, not the delusions or disorders that characterise it.
- 4. The five named characteristics do not comprise an exhaustive list, so that a state of mind may be rendered abnormal because of a number of characteristics only one of which must be one of the five listed in the first limb.

Whether this is in keeping with the original intention of the Act or not, this interpretation has both academic support²⁰⁶ and an accumulating body of case law behind it. Barring legislative review, it is likely to continue to be used. This has implications for 'marginal' cases such as anorexia nervosa. Based on this 'reverse' interpretation, if living in accordance with an anorexic identity sufficiently endangers a person's health or welfare, it could be considered an abnormal state of mind provided some aspect of her thinking fits one of the necessary criteria. Following the precedent set in *Re PFB*, the strong tendency of anorexics to resist treatment could also be used as evidence for the presence of mental disorder.²⁰⁷

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 $^{^{206}}$ See, for example, Dunlop N. 'Compulsory psychiatric treatment and 'mental disorder'.' NZLJ 2006; July:225-232.

²⁰⁷ "It makes good sense that the issue of necessity may be a relevant consideration as to whether or not a patient is mentally disordered, because the issue of compliance with treatment may impact directly and persuasively on the issue of whether or not the second limb is satisfied" *In Re PFB*, supra, n188 at 26.

5.2.1 Anorexia as an abnormal state of mind

Delusions and disorders of mood or perception have specific psychiatric definitions that are generally understood and accepted by the courts. An anorexia has been described as a disorder of perception (on the basis of body-image distortion), but while many patients see themselves as fat despite the physical reality of their weight loss, this is not universal. An anorexic that can pass a standard competency test must, by definition, understand and believe that she is dangerously underweight. Both depression and (in extreme cases) delusions can result from starvation. These are the result of the patient's physical state rather than characteristic of the illness *per se* (and can be resolved by limited weight restoration). Provided an end-stage or identity anorexic is not dangerously underweight, she would probably not be regarded as having a disorder of mood or perception. Disorders of volition and cognition are less clearly clinically defined, leaving judges freer to provide their own interpretations of these terms. Eating disorders are specifically mentioned in the Ministry of Health's guidelines on the Act as potential examples of impaired volition or cognition. This view is reflected in a number of Tribunal decisions, although not accepted *ipso facto*. ²¹¹

5.2.1.1 Anorexia as a disorder of volition

One of the difficulties in determining what the ordinary meaning 'volition' is the diversity of definitions of the word. Although 'volition' is not used diagnostically today, some medical or psychiatric states clearly change or remove a person's ability to control their actions (eg depressive stupor, command hallucinations, or disinhibited states following head injury). Other conditions where impulse control is impaired but a person remains aware of their actions are more problematic. While obsessive-compulsive disorder, eating disorders,

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²⁰⁸ Brookbanks W. <u>Mental Health Law in New Zealand</u>. Skegg PDG & Patterson S (Eds). Wellington: Brookers, 2006; Chapter 13: 'Mental Health Law'; p366-367.

For example, in *RCH* (MHRT/NR No 722, 20 April 2000) the Tribunal rejected the suggestion RCH suffered from a disorder of cognition on the basis that he did not suffer from a formal thought disorder. This decision was appealed in *Waitemata Health*, where Justice Elias stated (at 72):"It is difficult to see how H's personality disorder can be causative of the danger he is recognised to pose...except through disordered thinking or perception". A subsequent Tribunal found that RCH's 'overvalued ideas' constituted a cognitive disorder and authorised his continued detention under the Act. (MHRT/NR No 722/00, 20 December 2001).

Supra, n178 p13-14.

In CT (supra, n199), the Tribunal found that although anorexia was an abnormal state of mind, disagreements with clinicians, and non-compliance with the treatment programme were not evidence of disordered cognition or volition (although the fact CT was willing to seek other treatment and had a supportive family probably contributed to their willingness to release her from the Act).

The online Medical Dictionary describes volition as: "Voluntary action without external compulsion", the Shorter Oxford Dictionary as: "A decision of choice made after due consideration", and the Oxford Companion of Law as implying capacity to choose one course of action rather than another. In criminal law, volition is encompassed in the concept of 'mens rea', whereby an action is voluntary and intentional.

impulsive states such as borderline personality disorder or attention deficit disorder, psychosexual disorders, kleptomania, pyromania and pathological gambling could all be described as disorders of volition, not all are 'mental disorders' that could be ethically (or legally) treated.²¹³ Because the Act presumes a person has the right to choose (and accept responsibility for) their actions unless very specific criteria have been met, a broad definition of 'volition' would not be in keeping with the intent of the legislation.²¹⁴

Questions of volition have been considered in a number of court and tribunal decisions. In Re AC. 215 the tribunal emphasised that 'volition' needed to be interpreted in respect to the original legislative intent of the Act and outlined three parameters for consideration: treatability, the balance between need for compulsion and the imposition this imposes on personal liberty, and medical opinion that some disorder of will was involved in the condition.

There is a body of clinical opinion that anorexia is (partially) a disorder of volition. Personality traits such as restraint (the ability to resist temptation) and perfectionism (striving for control and the attainment of high personal standards) are commonly reported in research studies on people with eating disorders. On the other hand, decreased selfdirectedness (being responsible and disciplined), and obsessive-compulsive behaviour are also associated with both the development of anorexia and a poorer prognosis for recovery. 216 In some instances the involuntary nature of the behaviour is clear, sometimes even to the patient, such as *In the Matter of SCH*. ²¹⁷ Here, the patient refused to accept she had a problem but admitted she would binge if she had the chance, and that her binging behaviour crept up on her. The court took this as a powerful example of volitional disorder.²¹⁸ In other cases, the involuntary nature of the behaviour is not quite so clear, but a degree of flexibility in the interpretation can still allow the Tribunal to find volitional disturbance. In Re FAH, ²¹⁹ for example, it was argued that the patient's behaviour was not the result of an irresistible impulse, but of an impulse not resisted, and therefore she did not suffer from a disorder of volition. Because of the considerable difficulty distinguishing

²¹³ Supra, n178 p6.

For a detailed discussion of the complexities surrounding disorders of volition see Ruthe C. 'Volition-the rotten apple?' Butterworths Family Law Journal 1997; June:129-136.

²¹⁵ MHRT/SR No 52/94, 3 March 1995.

For a summary of this research see Lilenfeld LRR. et al. Eating disorders and personality: a methodological and empirical review. Clin. Psychol. Rev. 2006; 26(3):299-320.

²¹⁷ MHRT/NR No 696, 30 April 1999.

The Tribunal considered that compulsion was necessary to enable the patient to receive the assistance she needed so that her 'true self' to prevail over her eating disorder voice. ²¹⁹ Supra. n144.

between an irresistible and an un-resisted impulse, the Tribunal has tended to eschew this distinction in favour of assessing the outcome, ²²⁰ and here the argument was rejected on the basis that FAH's self-harming behaviour contradicted her expressed desire to continue living and was thus uncontrollable. 221 Although there is no contradiction between an anorexic who wishes to die and her actions, her suicidal intentions would taken as evidence of an irresistible impulse and thus an order of volition.

Another way in which the anorexic behaviour might be regarded as symptomatic of a disorder of volition is that the degree of control exerted by an anorexic is far outside what we consider 'normal.' The right amount of will is not fixed, and the degree of willpower that is appropriate will depend on situation and context: 222 A person who is morbidly obese would perhaps be expected to restrain his or her food intake and exercise more in order to lose weight, and may not be considered to have a disorder of will. In contrast, the normal, physiological response of a person who has been starved for a month would be to eat to excess until they had physically recovered, before reverting to a more balanced diet. An anorexic, however, exerts an iron will over her appetite, and appears unable modify that discipline to take into account the potentially fatal consequences of continuing to refuse food. 223 Although she is constantly hungry, the fear of losing control of her appetite overwhelms her desire to eat, and she may even train herself to experience hunger as pleasurable.²²⁴ This could be considered a disorder of volition, and would apply to an identity anorexic, even if there were no way to prove that her behaviour was the result of an irresistible (or unresisted) impulse.

5.2.1.2. Anorexia as a disorder of cognition

In psychiatry, the word 'cognition' is used to refer to the process of obtaining, organising and utilising sensory and perceptual information from the environment, past experience and

²²⁴ Bruch, supra, n22 p4.

 $^{^{220}}$ See, for example MHRT/NR 320/95, 17 May 1995.

²²¹This distinction could perhaps be made in respect of chronically anorexic patients for whom resisting anorexic impulses leads to such distress that they would rather refuse treatment suffer the consequences gaining weight, even if they understand this will result in their death.

222 The idea that will ought to be governed by reason can be traced back to Aristotelian virtue of prudence.

The principle of practical reason was further developed by philosophers such as Thomas Aquinas, for whom prudence represented the ability to apply practical reasoning to a specific act in a particular situation. The will can be mistaken in its choice of objectives, but free action cannot lead a person to act contrary to his own interests (as defined by a universal law). If it does so, this reflects not freedom of action but faulty reasoning. Stanford Encyclopedia of Philosophy: 'Medieval Theories of Practical Reason'.

http://plato.stanford.edu/entries/practical-reason-med/. Accessed 3rd February 2010.

Although hunger strikers or those undertaking religious fasts might exercise similar willpower, they would be exempt from the Act by virtue of the exclusionary rules in Section 4.

other mental activities. This could include both formal thought disorders such as psychoses, ²²⁵ and circumstances where a person's lack of insight and impaired judgement leave them unable to appreciate the life-threatening consequences of refusal of treatment.²²⁶ Under this definition, it is the *form* rather than the *content* of the thought that is important, analogous to the competence test applied under the PPPRA. This category could include other 'abnormal' mental processes such as the obsessive nature of the thoughts found in OCD, or the disordered self-perception in people with eating disorders. ²²⁷ although such emotive and judgemental descriptions are potentially prejudicial. In contrast, the Oxford English Dictionary definition of cognition includes both thought process and content.²²⁸ Despite concerns that this extended meaning could result in people with socially unacceptable ideas as meeting the legal definition of mentally ill (a situation probably never intended by Parliament), ²²⁹ this 'lay' definition that has been preferred by both Courts and Tribunals. 230 and a strictly psychiatric interpretation of the term (relating to thought process rather than content) has been explicitly rejected. Following the High Court decision in Waitemata Health, anorexic identity, by analogy with personality disorder, could also be considered a disorder of cognition. In *RCH* the tribunal adopted the definition of cognition given by the Concise Oxford Dictionary as: "the mental action or process of acquiring knowledge through thought, experience and the senses; a perception, sensation or intuition arising from this." RCH's hypersensitivity and sense of entitlement caused him to misattribute meaning to other people's behaviour to the extent that he considered women who showed him normal courtesy to be sexually attracted to him, and became violent when they rejected his romantic advances. Because his overvalued self-importance led to the flawed acquisition of knowledge, this was considered by the Court to be a disorder of cognition. Anorexia arises from what is, at least initially, a misperception about the individual's need for food and a pathological fear of weight-gain, which, in the case of endstage anorexia leads to her desire to die. For the identity anorexic, thinness gains an unusual

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McCarthy S. & Simpson S. In <u>Running a case under the Mental Health Act 1992</u>. NZ Law Society, 1996; Chapter 2: 'The statutory definition of mental disorder'.

²²⁶ Bell S. & Brookbanks W. Mental Health Law in New Zealand. Wellington: Brookers, 1998; p20.

Although in LB (supra, n74), the patient's body image disturbance was described as a disorder of volition and her obsessive desire to weigh herself as a disorder of cognition.

²²⁸ "Knowing, perceiving or *conceiving as an act...*" Concise OED, New Edition, emphasis mine.

²²⁹ McCarthy and Simpson, supra, n225.

The Guidelines to the MHA lists depression and mania (which alter cognitive rates), dementia, head injury, and the type of obsessive ruminations that occur in obsessive-compulsive and anxiety disorders, as disorders of cognition. Under certain circumstances, intellectual disability has also been found to meet the definition. See for example, *Police v Tetai* (District Court, Auckland CR 300400434, 11 February 1993); also known as *R v T* (1993) FRNZ 195. See also *Re JAB* (MHRT No 03/089, 13 August 2003).

importance in her world-view, and becomes a filter through which she interprets and experiences the world, leading to self-endangering behaviour.²³¹ The importance of thinness to an anorexic's sense of self could be considered an overvalued idea in the same way as RCH's narcissism, and thus a disorder of cognition. A similar analogy could be made of the identity anorexic's conviction that her need for security, self worth, etc, can only be met by maintaining an abnormally low weight.

5.2.2 Anorexia and danger to self

In the case of a severely anorexic patient, the physical danger is obvious. Similarly, the actions of an end-stage anorexic are, by definition, life threatening.²³² At what point, however, is an identity anorexic is endangering herself to the degree that intervention is legally (and ethically) justified? One way would be to set a threshold weight or BMI, but the point weight loss reaches dangerous level will depend on individual circumstances. It is not just a matter of immediate risks to physical health that needs to be assessed, but also the potential influence on recovery prospects of intervening, or *failing* to intervene. Because duration of illness is positively correlated with mortality rate²³³ and negatively correlated with the prospects of recovery,²³⁴ this could justify earlier intervention for patients with a history of anorexia compared to first-presentation cases, especially if previous relapses have reached life-threatening levels.

Even if an identity anorexic does not meet the 'danger to self' criteria, the refusal to meet what most would consider basic nutritional needs, social isolation necessitated by her eating and compensatory behaviours or even refusal of treatment could be considered as meeting the threshold for diminished self-care.

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In this sense, the form and content of anorexic thoughts could be regarded as inseparable, which further draws into question the adequacy of current competency criteria. For further discussion of this point see Gillett G. in Nature and Narrative: an Introduction to the New Philosophy of Psychiatry. Fulford B, Morris K, Sadler J, Stranghellini G (Eds). Oxford: Oxford University Press, 2003; Chapter 9: 'Form and content: the role of discourse in mental disorder'.

²³² Such patients are asking others to allow them to commit suicide.

Sullivan PF. 'Mortality in anorexia nervosa.' Am. J. Psychiatry 1995; 152:1073-1074.

Steinhausen HC. 'The outcome of anorexia nervosa in the 20th century.' *Am. J. Psychiatry* 2002; 159(8):1284-1293; Fichter MM. *et al.* 'Twelve-year Course and Outcome Predictors on Anorexia Nervosa.' *Int. J. Eat. Disord.* 2006; 39:87-100.

5.3 What is treatment for anorexia?

Treatment must have some relationship to the disorder, ²³⁵ but this can encompass a broad range of interventions. It may be a prerequisite for further therapy (such as returning an anorexic patient to a nutritional state where cognitive therapy can be introduced), treatment for the disorder, or possibly even for conditions that arise because of the disorder. Tribunals dealing with anorexic patients have drawn heavily on British case law, where force-feeding of anorexic patients has been found to constitute medical treatment for a mental disorder both as a way of relieving symptoms and as a prerequisite for psychiatric treatment of the underlying cause of illness.²³⁶ Therapy need not be limited to interventions aimed at weight restoration, however, and the definition of treatment recognised by the courts and Tribunals is a broad one, ranging from nasogastric feeding²³⁷ to social support.²³⁸ Treatment for anorexia involves a wide range of aspects in addition to weight restoration, and participation in all aspects of a programme, including occupational therapy, cognitive behavioural therapy, group, family and individual counselling could be included under the order. On the other hand, if treatment is of no therapeutic benefit, as in the case of LB, or a competent end-stage anorexic a Tribunal could reject an application for a treatment order because it futile and thus unnecessary.

5.3.1 *How long should compulsion continue?*

Part of the reason such a broad interpretation of 'treatment' has been adopted is that it is very difficult to define recovery from a mental disorder. 239 Given the concerns expressed by many clinicians about the deleterious effects of compulsion on the

²³⁵ "A proposed patient or patient may refuse consent to any form of treatment for mental disorder, except as provided...in section 110A." MH(CAT) Act s57.

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Riverside Mental Health NHS v. Fox. [1994] 1 FLR 614; South West Hertfordshire Health Authority v.

Brady (also known as re KB) (1994) 19 BMLR 144. These opinions were later upheld by the Court of Appeal in B v. Croyden Health Authority [1995] 1 All ER, a case where a patient with borderline personality disorder and self-harming behaviour was refusing food. These cases have subsequently been cited in a number of Tribunal findings in New Zealand, including Re FAH (supra, n144); In the Matter of LKR (SRT 40/2001, 22

August 2001).

August 2001).

Nasogastric feeding has recognised as medical treatment since the British case of *Airedale NHS Trust* v. Bland ([1993] AC 789).

See for example Justice Frater in Capital Coast Health v R ((1995) FRNZ 13 294; [1995] NZFLR838), cited in Re FAH): "[T]reatment should be aimed at addressing that disorder...through discussion and counselling...social interaction...a change or increase in medication-or a combination of all three. But all are valid forms of treatment."

²³⁹ In *Re FAH* (supra, n144 at 21) the Tribunal held that: " [While] there must be some *reasonable* prospect of it helping to alleviate the patient's condition...there is no requirement for successful treatment, a phrase which itself could be given a multiplicity of meanings ranging from holding deterioration in abeyance to total remission" (emphasis mine).

therapeutic relationship, it may be appropriate to reserve the use of the MHA for those patients who are in serious physical danger. The critical question often is not when to *invoke* commitment proceedings but at what point compulsion is no longer necessary and/or appropriate. Rebecca Dresser's argument in favour of using guardianship rather than mental health legislation to authorise compulsory treatment for anorexia is that it represents such an intrusion on the patient's autonomy and is so counterproductive that it should be revoked as soon as she is out of immediate physical danger. In chapter three it was argued that adopting an anorexic identity constrains a person's autonomy to the point that other considerations (including not only her welfare and best interests, but also the concerns of her family and society) can justify overriding her refusal of treatment. Identity develops over an extended period, and recovery involves relearning 'normal' behaviour, new coping skills and alternative ways of meeting the needs that anorexia satisfied. The physiological effects of starvation (including disordered eating behaviour) also take time to resolve. For this reason compulsory treatment may be necessary for longer than it takes to resolve the medical issues. New Zealand Tribunals have also recognised that treatment may take considerable time. In Re Jane, Judge McElrea acknowledged that the disorder does not disappear just because the patient puts on weight, and that ongoing counselling and care may be necessary. ²⁴⁰ Similarly, *In Re H* (a bulimic patient), Justice Inglis stated that the fact that the indicia of the mental disorder appear to have been controlled does not mean the disorder itself is resolved, and warns that premature discharge may lead to the recurrence of the problems that made the original order necessary.²⁴¹

Given the potential for the progressive loosening of restrictions that the MHA permits (for example the movement from inpatient to outpatient treatment orders), there is the potential for extended therapeutic involvement that may achieve longer-term improvements than are possible under the PPPRA.²⁴² Whether this is of any *practical* use is, however, uncertain. Although community treatment orders have been used in at least

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²⁴⁰ Supra, n18 p16.

²⁴¹ [1996] NZFLR 998 at p1005.

²⁴² In *Re CMC* (supra, n121) Judge MacCormick recognised that nasogastric feeding was not a long term cure, and was intended only to protect her from the consequences of continued food refusal and enable her to recover her capacity to make treatment decisions on her own behalf.

one Australian case to allow a patient to return to home,²⁴³ it is not clear *what* treatment could be enforced or monitored other than her weight or attendance at clinical appointments. This raises the question of why compulsion is necessary when the MHA could be re-invoked if necessary.²⁴⁴ Tribunals have warned that people cannot be expected to be perfectly well, and that at some point they need to take responsibility for maintaining their own health. Nor is the Act intended to allow indefinite detention on a preventative basis when a patient's condition is long-term stabilised.²⁴⁵ I suggest that anorexic patients should be released from compulsory orders at the point of discharge from hospital if it has not been done earlier.²⁴⁶

5.3.2 End-stage anorexia: The problem of release

What of a chronically ill patient who refuses treatment because she wishes to die? Although her motivation is based on an assessment of her quality of life rather than directly related to food and weight, the *reason* her life is unbearable is that her illness means that putting on weight leaves her feeling suicidal. Thinness is so important to her that death is preferable to living 'normally'. These characteristics would fit definitions of both a disorder of volition (she is driven by an uncontrollable impulse to starve) and cognition (she wants to die because she can't stand living with starvation, yet eating also makes her want to die). Thus, even if she was legally competent to refuse treatment, she could be treated under the MHA. In fact, there is a very real possibility that she could not be *released* from the Act if she was already under a treatment order.

In chapter three the case of LB was described. Although the Tribunal agreed that compulsion was no longer necessary (on the grounds of treatment futility), its members felt unable to discharge her from the Act because she remained mentally disordered. In reaching this decision, the Tribunal used a two-part interpretation of section 2, whereby the patient must be both no longer mentally disordered *and* 'fit to be released' before they can be discharged from the Act. A year after this tribunal hearing, the Court of Appeal in *Waitemata Health* specifically rejected this cumulative interpretation of s2 on the grounds it was inconsistent with the legislative scheme of the Act. In its decision the Court highlighted

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²⁴³ Anne, 2001. (Fieldwork observation, Mental Health Review Tribunal, Sydney NSW, 13 February 2001). Described in Carney 03, supra, n17 p662, 665-666.

 ²⁴⁴ If her weight falls below a certain level, or she fails to attend psychiatric or dietetic sessions, for example.
 245 Re JIP (MHRT/SR No 02/209, 19 November 2002)

In fact, this return to the anorexic of responsibility of maintaining her recovery outside hospital could be regarded as an important part of the treatment.

that the only purpose of compulsory status is to achieve assessment or treatment and that the Act was designed to respect the human rights of those subject to its provisions. Ironically, its alternative interpretation that a person is fit to be released because they are no longer mentally disordered and therefore fit to be released (which they considered was consistent with the statutory structure) would, in the case of LB, lead to the same, unfortunate result. This is morally wrong. The third criterion that must be satisfied in order for compulsion to be ethical is the availability of *potentially effective* treatment. The use of compulsion can only be justified if treatment is likely to provide benefit to the person subject to coercion, yet it is very clear that intervention worsened LB's condition. Such action would be prohibited by the principle of non-maleficence, regardless of whether her resistance was the result of an autonomous decision or driven by her illness.

Not only is coercion in this instance ethically unjustifiable, it is also legally questionable. The purpose of the Act to protect the rights and interests of person's suffering from mental disorders, and 'treatment' in this instance was clearly not the patient's best interests. Using it to detain a person without providing any therapeutic benefit is thus contrary to the original intention of the Act. It also potentially breaches her rights under section 6 and 22 of the New Zealand Bill of Right Act not to be subject to torture or to cruel, degrading, or disproportionately severe treatment or punishment, and not to be arbitrarily detained. Although the MHA supersedes the Bill of Rights, it should, when possible be interpreted in a manner consistent with those rights.²⁴⁷ The simplest method of resolving this problem would be to determine the necessity for treatment every time a compulsory treatment order is reassessed or an application made for release. This would also be consistent with the finding of the High Court in Waitemata Health that the threshold for release should be the same as for the imposition of compulsory treatment.

5.4 Competence and the MHA

The courts have recognised that not all people who meet the legal definition of a mentally disordered person in the mental health legislation are necessarily incompetent. Although illness may reduce a person's capacity to make informed treatment decisions, mental illness and competence are not mutually exclusive. In a precedent setting British case, In Re C, 248 a schizophrenic patient was considered competent to refuse the amputation of a leg because his general capacity to make medical decisions remained intact, and his reasons for refusing

²⁴⁷ MH(CAT) Act s6.

²⁴⁸ [1994] 1 WLR 290.

treatment were unrelated to the thoughts associated with his schizophrenia. Whether this extends to treatment decisions related to a person's *mental* disorder is problematic, however. Both British and New Zealand mental health legislation authorise clinicians to provide any treatment necessary for the patient's mental illness, ²⁴⁹ with no requirement for the patient's competence to be respected. This has caused disquiet among some commentators because it may conflict with concepts of human rights.²⁵⁰

Although the s57 of the MHA affirms the basic right of a patient to refuse treatment for a mental disorder, this is specifically abrogated during the pre-committal assessment period and the first month of a compulsory treatment order. 251 Even after this period, a Tribunalappointed psychiatrist may override a patient's objections if he or she considers treatment to be in that person's best interests.²⁵² In recognition of the fact that mental illness often fluctuates over time, the MHA also allows for the compulsory treatment of patients whose illness in intermittent. This is particularly important if the patient has a history of severe or prolonged relapse, but raises the possibility that once a person is found to have a mental disorder under the MHA, they could be forced to accept treatment that they would have been allowed to refuse if the matter had been pursued under the PPPRA. In isolated cases, questions of competence have been considered. For example in Re S, 253 a case taken under the 1969 Mental Health Act, Justice Barker considered that a patient had the right to refuse mental health treatment had he been competent to do so. Similarly, in Re K, Judge Inglis reaffirmed that a patient's right to self-determination was too important to ignore just because treatment was good for her, and that the essential question was the degree to which that person's choice was influenced by her mental illness.²⁵⁴

Questions of competence under the MHA are, however, seldom addressed unless raised specifically by the patient in review or appeal.

 $^{^{249}}$ Although some procedures require additional authorisation; Part 5 MH(CAT) Act.

²⁵⁰ It has also been question in Britain following the Court of Appeal decision in *R v Broadmoor Hospital* [2001] EWCA Civ 1545. ²⁵¹ MH(CAT) Act s58.

²⁵² Ibid, s59(2)(b).

²⁵³ [1992] 1 NZLR 363.

²⁵⁴ Re K (2002) 22 FRNZ 349; [2003] NZFLR 318. Despite Mrs K acknowledging her illness, the judge found that her lack of insight into the consequences of stopping her medication (which might occur if it were not compulsorily administered) prevented her making a competent decision to refuse treatment.

CHAPTER SIX: HOW OUGHT THE LAW TO HANDLE END-STAGE AND IDENTITY ANOREXIA?

6.1. Summary

Anorexia presents an example where the differences between the jurisdiction of the PPPRA and the MHA are clearly revealed. If we believe that anorexia undermines a person's ability to make reasoned treatment decisions, either the MHA or the PPPRA could be used to enforce treatment, and intervention could be justified if we consider that the patient's health and welfare are seriously endangered. This appears to be true for the majority of anorexic patients placed under compulsory treatment orders. On the other hand, if we accept that some anorexics might remain competent to accept or reject treatment for reasons unrelated to areas of focal incompetence (food and weight), an application for compulsory treatment might be rejected under the PPPRA but accepted under the MHA. In the case of end-stage anorexia, life-sustaining treatment should still not be obligatory if its burdens outweigh the benefits to the patient. The lack of a 'necessity' test in dealing with requests for release from the MHA may mean such a patient is unable to be discharged if they remain mentally disordered, while the absence of a competency test means that a patient's legitimate rejection of treatment may be overruled. This provides a strong moral argument for the use of the PPPRA in such cases. In contrast, there are reasons to regard an identity anorexic's autonomy as compromised even though she may meet current competency criteria (depending on how broadly they are defined by the Court), suggesting the use of the MHA is more appropriate.

6.1.1 The ethical position

Based on a principlist analysis and weak paternalism, a person's choices must be respected unless they are acting non-autonomously, and any intervention must be in their best interests. Under such a framework, compulsory treatment of an anorexic patient is ethically justified if and only if:

- 1. She is treatment resistant.
- 2. Her health and welfare are seriously endangered.
- 3. Potentially effective treatment is available (and would not be undermined by the use of compulsion).

4. The ability to make relevant decisions in an autonomous manner is compromised by her illness.

Applying these principles to the two categories of patient considered in this dissertation, I conclude the following:

An end-stage anorexic is treatment resistant and her health and welfare are seriously endangered, but because there is no potentially effective treatment, the use of compulsion is not justified (regardless of whether her refusal of treatment is autonomously made or not).

An identity anorexic is treatment resistant, her health and welfare are seriously endangered, potential treatment is available, and her decision is compromised by her illness. In addition, respecting her negative autonomy may further compromise her positive autonomy, and thus the use of compulsion is justified.

6.1.2 The legal position

Based on this principlist analysis, the two Acts are not only incompatible with respect to whether the use of compulsion is lawful, each of them permits ethically unacceptable treatment of one of the two groups of anorexic patient. An end-stage anorexic may be found competent under the PPPRA but may be unable to be released from 'treatment' under the MHA despite the fact it has no potentially effective therapeutic benefit. In such cases, the use of the PPPRA is preferable and the use of the MHA is unethical. Similarly, an identity anorexic may be found competent under the PPPRA, but may be compulsorily treated under the MHA. In this case, however, the use of the MHA is preferable (and the use of PPPRA may be unethical if her ability to recover is impaired because she does not receive treatment). This situation is both legally and ethically unsatisfactory, but just as ethical analysis highlights the difficulties with the law as it stands, it also suggests how these could potentially be resolved.

6.2 Conclusions

There are two options available to ensure that the law does not authorize unethical treatment. The first option is to retain the status quo, with the understanding that cases of end-stage anorexia should be dealt with exclusively under the PPPRA, with identity anorexics treated under the MHA. Although this is the simplest solution, this option

remains problematic for several reasons. Firstly, ethical analysis reveals that an identity anorexic is not acting with full autonomy when she rejects treatment. Despite this, she could potentially be considered legally competent to do so. This raises questions about the adequacy of current competency criteria, and whether decisions currently considered legally competent are necessarily the product of autonomous choices as we normally understand them. This concern is not necessarily specific to anorexia, and there may be other illnesses where a treatment-resistant patient may remain legally competent but whom we think ought to receive therapy.²⁵⁵

Secondly, the lack of a competency assessment in the MHA raises the possibility that anorexic patients may transition into the end-stage category but be unable to be released from the Act. The lack of a 'necessity' test in the reassessment of compulsory treatment orders under the MHA could also prevent the release of anorexics (or any other mental health patient) for whom compulsory treatment is subsequently judged futile.

This leads to the second potential solution, which is to amend the two Acts to address these specific ethical concerns.

6.2.1 Changes to the PPPRA

The first change I propose is to define 'competence' in the PPPRA in such a way that it better reflects what we consider autonomous decision-making. There are several ways in which this could be achieved, but care needs to be taken to ensure that it is not set so high as to capture people whose freedom we would not normally consider restricting.

6.2.1.1 'Pathological values'

Part of the reason for excluding thought content from the competency assessment is that people act for a wide variety of reasons that are not always comprehensible to others but reflect their own values and beliefs.²⁵⁶ We could, however, accept that what we consider normal or abnormal behaviour is, to a large extent, a reflection of social and cultural values (hence overeating is a moral failing, under-eating a mental disorder), and adopt a substantive rather than a procedural definition of competence. The thoughts and values that drive anorexic behaviour and define anorexic identity are so far outside anything we would

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²⁵⁵ Jacinta Tan (supra, n163) gives the example of a clinically depressed patient who refuses treatment because she feels worthless and undeserving of attention. The depression affects the values she uses to weigh up her decision, but not her intellectual capacity to *make* that decision.

²⁵⁶ People get drunk for fun, drive racing cars for the adrenaline buzz, or refuse to immunise their children because they trust complementary medicine more than allopathic practice.

generally regard as 'normal' perhaps thought content should be evaluated in relation to some normative standard. Such a 'pathological values' test would look not only at a proposed patient's thought processes, but also at the *content* of those thoughts. If the values and preferences that influence a person's decision are highly unusual and influenced by injury or illness, this could be regarded as evidence for impaired competence in the same way it is currently regarded as indicating cognitive disorder under the MHA.

This can be ethically justified because we are respecting the autonomy of the 'authentic' patient (ie, what she would have chosen if she were not ill), but it is not clear that the values an anorexic ascribes to (such as thinness) are in themselves unusual. We live in a society that places a great deal of importance on weight and weight loss, and what distinguishes an anorexic from a 'normal' dieter is not the value itself, but fact that it takes priority over all other concerns.²⁵⁷

6.2.1.2 'Appreciation'.

An alternative approach would be to look not at the thoughts themselves, but at the effect they have on a person's decision. We might accept an anorexic is refusing treatment because she considers thinness so important she is prepared to risk death or debilitation rather than put on weight, but ask her *why* it is so important. As discussed in chapter two, an anorexic's behaviour can be purposeful and provide real and demonstrable benefits to her that she is reluctant to put at risk. For her, thinness derives its meaning in part from these advantages, and in part from what it signifies (self-restraint, moral virtue, etc). There are other ways in which these needs and values can be realised, but the anorexic seems to be unable to imagine that this is possible. Similarly, for an identity anorexic, recovery may be meaningless because she is unable to imagine living any other way, or the existential threat it represents overwhelms her with fear. Because of this, her ability to understand the options *as they apply to her* is impaired. This is a preferable option because it formalises the already tacit requirement for a salient belief as applied in the current competence test, rather than adding additional criteria.

Grisso and Applebaum have suggested a person might fail an appreciation test if her wider belief system influences her decision and:

- The belief is highly unrealistic, irrational or substantially distorts reality.
- It arises from impaired cognition or affect.

²⁵⁷ For a more comprehensive discussion of this subject see Tan 06, supra n163.

• It is relevant to the treatment decision. ²⁵⁸

This has been adopted into the clinical MacCAT test of competence, 259 but Jacinta Tan has argued that this does not resolve the problem of illnesses that influence value judgements rather than beliefs. When an anorexic considers her 'sick' identity more important than any benefits she might derive from treatment, she is expressing a value choice rather than a belief about the world, and many anorexics Tan interviewed met the MacCAT criteria. One way to address this criticism is to regard a person as lacking in 'appreciation' if they are able to imagine the potential outcomes of a decision for everybody but themselves. 'Understanding' in the PPPRA could be defined in the manner suggested by Buchanan and Brock as:

[T]he ability to appreciate the nature and meaning of potential alternatives – what it would be like and "feel" like to be in possible future states and to undergo various experiences – and to integrate this appreciation into one's decision making.²⁶⁰

This lack of understanding would still need to be linked to injury or illness to prevent setting the bar of competence so high that it would be failed by a significant proportion of the population (especially adolescents). ²⁶¹ It would, however, be failed by most identity anorexics and in other marginal cases where people may remain procedurally competent but treatment could be ethically justified. In incorporating an assessment of emotional as well as procedural competence, this revised assessment would be very close to that suggested by Gans and Gunn for assessing end-stage anorexics. Because the Gans and Gunn model has the advantage of involving and supporting friends and family of the patient, however, I recommend their criteria be recognised as necessary and sufficient for an anorexic's advance directive to be legally recognised.

²⁵⁸ Grisso T. & Applebaum PS. In <u>Assessing competence to consent to treatment: A guide for physicians and</u> other health professionals. London: Oxford University Press, 1988; Chapter 3: 'Abilities related to competence'; p31-60.

Grisso T. et al. 'The MacCAT-T: a clinical tool to assess patients' capacities to make treatment decisions.' Psychiatr. Serv. 1997; 48(11):1415-1419.

²⁶⁰ Supra, n135, p24.

²⁶¹ As Jacinta Tan (supra, n163) points out, under too strict a definition no teenager (and many adults; 80% of New Zealanders consider themselves above average drivers according to some surveys) should be considered competent to get behind the wheel of a car. This might well be desirable, but would constitute a considerable infringement on personal liberty.

6.2.2 Changes to the MHA.

The biggest difficulty with the MHA as it currently stands is the possibility that patients under indefinite orders may be compelled to accept futile treatment. The simplest way to resolve this is to apply the same necessity test to every application heard by the Review Tribunal. I also suggest that the revised competency test described above be incorporated into the MHA with respect to treatment. This would obviate human rights concerns, and ought not lead to detention without treatment: If a patient is competent to refuse treatment he or she ought not be forced to accept it, and if there is no alternative treatment available, a treatment order would fail the necessity test. These conclusions are supported by the same ethical analysis that applies to the anorexic patients considered in this dissertation.

6.2.3 Proposed amendments.

In order to align the PPPRA and the MHA both legally and ethically, I suggest the following changes:

- 1. "Understanding" should be defined in the PPPRA as being not only the ability to understand and retain relevant information, but also appreciation: "The ability, unimpaired by illness, injury or intellectual disability, to imagine what the potential consequences of treatment refusal *and* acceptance would be like and feel like, and to integrate this appreciation into one's decision making."²⁶²
- 2. This clarified competency test ought to be included in the MHA as a criterion for compulsory treatment.
- 3. The 'necessity' provision of s27 of the MHA should be applied whenever a treatment order is reassessed.

This does not automatically mean that all but end-stage anorexics should be subject to compulsory treatment. The availability and efficacy of therapy is an important consideration in determining whether such intervention is necessary or appropriate. The limited nature of comprehensive eating disorder programmes in New Zealand may need to be addressed before such changes to the law were introduced.²⁶³

 $^{^{262}}$ A person would thus fail the competency test if illness or injury influenced their salient belief.

Although such changes may have ramifications for other 'marginal' cases, this is beyond the scope of this dissertation. These would also need to be considered before any changes to either Act.

6.3 Closing remarks

In some cases, we may be ethically obliged to accept an anorexic's choice to refuse treatment on the basis that her standard of life and her prospects of recovery are so poor that she no longer wishes to live. Although she may indeed be competent to make this decision, the principles of non-maleficence and beneficence require us not to enforce futile or counterproductive treatment even if we are not convinced she is acting with full autonomy.

There is a stronger justification for intervening in cases where an anorexic refuses treatment because she would rather live with her condition because the benefits of remaining as she is outweigh the risks. Firstly, these ideas and values that underlie this choice, regardless of their aetiology, come to hold such overwhelming significance that they overwhelm her ability to make autonomous decisions. This is manifest in the fact that she does not wish to die, yet continues to engage in behaviours that put her life and health at risk. While she may understand the risks she is taking at an intellectual level, she may not be able to fully apply them to herself. Conversely, she may be unable to choose an option that might result in recovery because she is unable to imagine life without her illness. At the very least, her desire to live entitles us to intervene when *involuntary* aspects of her behaviour place her life in danger. Secondly, her social autonomy is limited by the anorexia. Respecting her negative autonomy (the right not to have her choices interfered with) prevents or even impairs the advancement of her *positive* autonomy (the ability to fully engage in what we consider a full and meaningful life). Not only is the normative strength of her autonomy weakened, the principle of beneficence suggests that we should act to enable her to live a more fulfilled life. Thirdly, there is the potential for significant harm to friends and family affected by her illness, and to wider society of accepting anorexia as a valid lifestyle. A final point that I would like to make is that even 'voluntary' treatment is frequently the result of intense pressure from friends, family, medical and psychiatric professionals. It is sometimes accompanied by the threat of compulsion if the anorexic does not comply. Taking all of these factors into consideration, on balance it appears that involuntary treatment *can* be effective under the right circumstances.

In saying this, I acknowledge this view is partly shaped by my own experience, based both to the central role that self-definition played in my illness, and my profound gratitude to those who impelled me towards discarding that identity and finding that there was a larger one for me to fill.

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