

# ANOREXIA NERVOSA AND RESPECTING A REFUSAL OF LIFE-PROLONGING THERAPY: A LIMITED JUSTIFICATION

---

HEATHER DRAPER

## ABSTRACT

*People who suffer from eating disorders often have to be treated against their will, perhaps by being detained, perhaps by being forced to eat. In this paper it is argued that whilst forcing compliance is generally acceptable, there may be circumstances under which a sufferer's refusal of consent to treatment should be respected. This argument will hinge upon whether someone in the grip of an eating disorder can actually make competent decisions about their quality of life. If so, then the decision to refuse therapy may be on a par with other decisions to refuse life-prolonging therapy made by sufferers of debilitating chronic, or acute onset terminal illness. In such cases, palliation might justifiably replace aggressive therapy. The argument will also draw heavily on the distinction between competent refusal of therapy and passive euthanasia, and the distinction between incompetent and irrational decisions. Both distinctions will then be applied to decisions to refuse food. The extent to which sufferers from anorexia nervosa can be categorised as either incompetent or irrational will be examined. It is against this background that it will be argued that at least some of those who suffer from eating disorders should have their refusals respected, even if they may die as a result.*

---

## INTRODUCTION

The eating disorder anorexia nervosa results in the death of between 20–30 patients per year in the UK<sup>1</sup> and death rates

<sup>1</sup> Crisp, *Anorexia Nervosa: Let Me Be* (Baillere Tindell, London, 1990), p. 31.

internationally are reported to be between 4–20%.<sup>2</sup> This death rate would undoubtedly be higher if anorexics were not force-fed once their weight became dangerously low. Force-feeding (feeding without consent) has been recognised in the UK by the Mental Health Commission as a legitimate therapy to give under section 63 of the UK Mental Health Act 1983,<sup>3</sup> and the legitimacy of force-feeding in conjunction with other therapies is also supported in case law.<sup>4</sup> Force-feeding may take the form of literally forcing a patient to eat; coercing her to eat by putting her under pressure to feed herself; or, by tube feeding. Feeding alone is thought to be ineffective – unless it is done simply to restore the patient sufficiently to enable her to participate in other psychiatric therapies. Sectioning for feeding should, therefore, only be considered as an adjunct to other therapies if it is to be justified by appeals to best interest. It is also thought likely that repeated episodes of force-feeding – particularly of the literally forcing food into the mouths of sufferers kind – decrease the chances of long-term recovery and it is doubtful that it is actually in the best interests of a patient to be subjected to a regime of force-feeding on more than a few occasions.<sup>5</sup> Nevertheless, medical practitioners are understandably reluctant not to force-feed by one method or another when a patient is dying for want of nutrition. A recent article<sup>6</sup> suggesting that there might be a role for a palliative approach for patients who are both long term sufferers and refusing therapy, attracted more criticism than support from practitioners, and the possibility of respecting a sufferer from anorexia's decision not to proceed with therapy – whatever the circumstances – has been described

<sup>2</sup> The death rate varies according to study and length of follow up. For instance, see Phillip W. Lang *The Harvard Mental Health Letter*, Oct./Nov. 1997 who also cites a prevalence for anorexia nervosa of 0.1–0.6% in the general population in the USA (a figure which he claims is several times higher amongst adolescent girls).

<sup>3</sup> Mental Health Act Commission *Guidance Note 3: Guidance on the Treatment of Anorexia Nervosa Under the Mental Health Act 1983* (Issued August 1997).

<sup>4</sup> See *Riverside Health NHS Trust v. Fox* [1994] 1 FLR and *B v. Croydon H.A.* [1995] 1 AUER 683.

<sup>5</sup> This argument was made very forcefully by Penny Lewis 'Feeding anorexic patients who refuse food', *Medical Law Review*, 7, 1, (1999), pp. 21–37.

<sup>6</sup> J. O'Neill, *American Journal of Hospice and Palliative Care* Nov./Dec. 1994 pp. 36–8. In 1998, the *British Medical Journal* 18 July 1998 pp. 195–197 also addressed the issue of palliation in its 'Education and Debate' section. In this discussion, C. J. Williams, L. Pieri, & A. Sims, argued that patients should always be treated actively, whilst L. Russon, & D. Alison, argued that there was a case for extending palliative care to anorexics.

as collusion.<sup>7</sup> It is asserted that sufferers from anorexia are not competent to make any decisions that relate in any way to food, and withdrawing therapy or treating palliatively effectively entails withdrawing feeding. On one level this assertion may be pointing out the obvious – someone who is on the point of starving to death, has uncontrollable (non) eating behaviour and a completely distorted body image is not likely to be competent. Such an assertion, however, assumes that incompetence is a description of an individual (broad or global incompetence) rather than an assessment of the capacity of the individual to make a specific decision (narrow incompetence). Some anorexics may indeed be incompetent as individuals (be broadly incompetent): for example, those on the point of starving to death. Others are certainly not broadly incompetent; they are studying for school leaving exams, or degrees, or are running their own financial affairs, others are professionals working in demanding jobs. It is because incompetence is also task specific (narrow) that it is accepted that a patient who is sectioned for compulsory treatment for a specific mental disorder cannot be treated on an involuntary basis for any other health problem, however life-threatening it is thought to be.<sup>8</sup> Thus, sufferers from anorexia cannot be involuntarily subjected to any therapies unrelated to their eating disorder. But could an anorexic competently decide to withdraw from therapy not on the grounds that she didn't want to eat, nor that she was 'fat' but because the quality of her life was so poor that the therapy was no longer of benefit to her, or that it was on balance more of a burden than a benefit?

In this paper, it is argued that whilst it is generally legitimate to detain and treat sufferers from anorexia against their will, under some circumstances there is a failure to respect their competent refusal of therapy; namely where those who are refusing have been afflicted beyond the natural cycle of the disorder (which is between one and eight years); have already been force-fed on previous occasions; are competent to make decisions concerning their quality of life; have insight into the influence which their anorexia has over some aspects of their lives, and are not at

<sup>7</sup> Janet Treasure speaking at 'Food, Glorious Food?', Kings College, London 4th July 1997.

<sup>8</sup> In one dramatic example a patient, who was sectioned for treatment for paranoid schizophrenia, refused to have his leg amputated even though medical advice was that the gangrene would otherwise kill him. A court upheld his right to refuse treatment on the grounds that he was competent to do so. *Re C* (refusal of medical treatment) [1994] 1 All ER 819 (FD).

death's door (they may, for instance, have just been released from a section for compulsory treatment). It will be argued that in these cases, the decision to refuse therapy is on a par with other decisions to refuse life-prolonging therapy made by sufferers of debilitating chronic, or acute onset terminal illness and that in such cases palliation might justifiably replace aggressive therapy. In order to do this the paper will first revisit the distinction between competent refusal of therapy and passive euthanasia and the distinction between incompetent and irrational decisions. Both distinctions will then be applied to decision to refuse food. Finally, the extent to which sufferers from anorexia nervosa can be categorised as either incompetent or irrational will be examined. It is against this background that it will be argued that at least some of those who suffer from anorexia should have their refusals of therapy respected, even if they may die as a result.

#### THE DISTINCTION BETWEEN PASSIVE EUTHANASIA AND COMPETENT REFUSAL OF LIFE-PROLONGING THERAPY

A distinction is drawn in many jurisdictions between passive euthanasia – which may be viewed as murder or a similar crime – and respecting a competent patient's decision to refuse life-saving or life-prolonging therapy – which is part of respecting the right to consent. This distinction can also be important in ethics where passive euthanasia is considered wrong, but respecting a patient's decision to withdraw or withhold therapy is not only permissible but may be required.<sup>9</sup> Clearly, the distinction is irrelevant for those who think that euthanasia can be permissible, but for those who disagree, it is perceived to form the boundary between acceptable and unacceptable withdrawal of therapy. The distinction will be used in this paper to argue that whilst it might be wrong for clinicians to give up on anorexics, and therefore for them to decide to withdraw therapy, it is acceptable for the anorexic herself to make a decision to withdraw from therapy, under certain circumstances and for reasons which will be addressed in the second half of this paper. So, can the distinction between passive euthanasia and competent withdrawal from therapy be defended?

<sup>9</sup> For instance, it might be argued that whilst it is acceptable to take one's own life, it is wrong to enlist the help of others in so doing, or that it is wrong for doctors to take life, or that permitting any form of euthanasia is the first step on a dangerous slippery slope.

In passive euthanasia therapy is withdrawn or omitted with the intention that the patient will die as a result. To be euthanasia, the omission or withdrawal must be thought to be in the patient's best interests, whether or not the patient is party to this decision.<sup>10</sup> The final judgement about whether or not to omit therapy rests with the clinician and not the patient, even when the patient is party to the decision, or even when the patient goes to considerable lengths to persuade the clinician of her point of view. The judgement which the clinician has to make is whether in his view the quality of the patient's life is such that the patient is better off dead, for this is what it means to act in the patient's best interests in the context of euthanasia. Considerable weight may be given to what the patient thinks. The clinician may even decide to be bound by what the patient thinks, but the final decision still rests with him: it remains his decision that the most significant factor in determining whether the patient's life is worth living is that the patient thinks that it isn't. The decisive part played by the clinician's judgement is most obvious where the clinician and patient disagree. Take an extreme case of a terminally ill patient, dying in great pain trying to convince a 'pro-life' clinician that she would be better off dead. Because the clinician believes that any life – irrespective of its quality – is better than no life at all,<sup>11</sup> nothing that the patient says will convince him to agree to co-operate in the withdrawal of therapy on the grounds that the patient is better off dead. However, if the patient simply said that she withdrew her consent for the therapy to continue, the clinician would have to comply but would comply without compromising his view that her life was worth living. When a competent patient refuses therapy – whether or not she has a terminal illness or a poor quality of life or will die as a result – professional carers are ethically and legally bound to accept this refusal.

The moral difference between passive euthanasia and competent refusal of therapy lies in who makes the final decision. Euthanasia is something which one person gives to another – whether or not it is voluntary. Withdrawing from therapy is something which one does to, or for, oneself. Respecting autonomy means that we bound to take our own

<sup>10</sup> For more on the definition of euthanasia and distinctions between euthanasia and other forms of killing – including self-killing – see Heather Draper 'Euthanasia' in *Encyclopaedia of Applied Ethics*, ed. R. Chadwick, (Academic Press, San Diego, 1997). pp. 175–187.

<sup>11</sup> For an example of such an argument see Thomas Nagel, *Mortal Questions* (Cambridge, Cambridge University Press, 1979).

moral decisions and others are bound not to interfere; but it also means that we are responsible for the decisions which we make. There is, then, a strong sense in which clinicians are responsible for decisions to give euthanasia, and patients are responsible for decisions which they make to withdraw from therapy.<sup>12,13</sup>

## DISTINCTION BETWEEN IRRATIONAL DECISIONS AND INCOMPETENT DECISIONS

Patients can refuse therapy for a variety of reasons. They may have religious objections to some procedures which are life saving (like Jehovah's Witnesses do to blood transfusions); they may have moral objections (perhaps a strongly held view that it is wrong to terminate the life of the unborn even to save one's own life); they may be objecting on economic moral grounds (believing that the money which is to be spent on them would be put to better use saving someone else); they may hold the personal belief (whether or not well founded) that they have become too much of a burden upon their family; or, they may consider that the burden of the therapy has become too great so that even though they would rather live, they would rather risk dying than continue with this therapy. None of these reasons requires us to be convinced that it is in the patient's best interests to be dead – as would be necessary in passive euthanasia – but any of these reasons given by a competent patient would be sufficient to suppose that her decision should be respected.

Of course, we might want to argue that it is irrational to put religious beliefs before life itself – particularly when the religious belief is based on a literal interpretation of the bible. We might argue that it is irrational to prefer to save the life of an unborn child to one's own, particularly if the unborn child may die anyway as a result of one's own death. We might argue that it is irrational to give up one's own chance of life when one has no control over where the resources will be spent instead. We might argue that it is irrational to perceive oneself as a burden to relatives because burdensomeness is in the eye of the beholder.

<sup>12</sup> Though, as one of the referees for this paper helpfully pointed out, there is a sense in which a patient who goes to great lengths to persuade a clinician to perform euthanasia upon her, shares some of the responsibility for her own death. More generally this point is well taken because otherwise we would be able to avoid responsibility for any action by persuading an accomplice to undertake it for us.

<sup>13</sup> Obviously, some people would want to argue that voluntary euthanasia also respects the autonomous decision of the patient.

But we should be wary of confusing *irrational* reasons with reasons with which we simply *do not agree*. Furthermore, we should be wary of confusing either irrationality or strong disagreement with incompetence.

When determining incompetence, we could do worse than adopt the so-called *Re C* test outlined by J. Thorpe: competence requires ‘... first comprehending and retaining treatment information, secondly believing it and thirdly, weighing it in a balance to arrive at a choice’.<sup>14</sup> Clearly, applying this test might be difficult – for instance, perhaps the patient is right to be sceptical about the information which is given by a clinician under some circumstances<sup>15</sup> – but the test itself seems reasonable.

The distinction between being incompetent and being irrational has been consistently defended in court. Although it is recognised that irrationality may be a *symptom* of incompetence, it is not by itself a *sign* of incompetence. This legal distinction between irrationality and incompetence was reiterated in the UK in February 1997 when L.J. Butler-Sloss upheld J. Hollis’ decision that it would not be unlawful for MB to have a caesarean section against her wishes.<sup>16</sup> It was submitted that an irrational fear of needles was intermittently rendering MB incompetent to refuse her consent to the caesarean section to which she had consented (on more than one occasion) when she was away from the operating theatre or not being offered a pre-med. In upholding the judgement, Butler-Sloss pointed out that an irrational fear of needles was *not* sufficient ground for overriding the refusal of surgery (despite the risk of harm to the foetus), nor did she think that the patient was incompetent to make any decision because she had this irrational fear. Rather she argued that MB was competent whilst *consenting* to the operation away from the theatre and was rendered *incompetent* by needle phobia (fear and panic) when the operation was imminent and that this phobia was actually preventing MB from doing what she wanted to do. Accordingly, it was not wrong to override the incompetent desire in favour of the competent one because having the caesarean

<sup>14</sup> *Re C* (refusal of medical treatment) [1994] 1 All ER 819 (FD) at p. 36.

<sup>15</sup> For instance, it could be that the clinician is being over optimistic, or is trying to give the patient hope. There may even be a difference of medical opinion about what is best to do, or very little evidence that what is recommended is actually an effective course of action – see Heather Draper ‘Women, forced caesareans and antenatal responsibilities’, *Journal of Medical Ethics*, 22, 6, (1996), pp. 327–333.

<sup>16</sup> *Re MB* [1997] 8 Med. L. R. 217.

section was what her competent self had repeatedly asserted that she wanted to do.

To summarise, a competent decision to refuse therapy can be made on rational or irrational grounds, or even no grounds at all. A request for voluntary, passive euthanasia, however, must, in addition to being competent, be rational to the extent that the doctor concerned can be persuaded to become party to the decision. But the doctor can also refuse to be party to the decision not because it is an incompetent one, nor because it is an irrational one, but because he disagrees that euthanasia is the appropriate clinical or moral option under the circumstances. At least two things follow from this distinction. The first is that patients who might otherwise request passive euthanasia could instead refuse of all therapy necessary to sustain or save life. If food is considered to be a therapy,<sup>17</sup> then no competent patient is without the means to end her life since she simply has to refuse to eat and decline her consent to tube feeding. The advantage of so doing is that it is not necessary for the patient to make the clinician an accomplice to her decision. This does not mean that she has to conceal her desire for death from her clinician – indeed, this desire is likely to be discussed when any patient makes such a request. Rather it means that the patient remains in control, since it is her decision, rather than that of her clinician, which is the decisive one. The second is that since it is already legal for competent patients to refuse therapy, there is no need, in addition, to legalise voluntary, passive euthanasia in order to give patients autonomy over their own bodies. Both these arguments may meet some of the ethical problems with euthanasia previously outlined.<sup>18</sup>

## REFUSAL OF FEEDING

But can these distinctions between voluntary passive euthanasia and competent refusal of consent be applied to feeding? It certainly seems so, for a decision to withhold/withdraw tube-feeding from an incompetent patient on the grounds that their interests were best served by being dead would certainly be euthanasia,<sup>19</sup> whilst competent decisions to refuse food (whether by tube or other means) are not.

<sup>17</sup> In the UK, it was established that tube-feeding was a medical intervention in *Airedale NHS Trust v. Bland* [1993] 3 WLR 316.

<sup>18</sup> See the points made in footnote 9.

<sup>19</sup> This point is well made by James Rachels 'Active and Passive Euthanasia' in *Applied Ethics* ed. Peter Singer, (Oxford University Press, Oxford, 1986) pp. 29–35.



Once more, the distinction seems to turn upon who makes the final decision, the doctor (in euthanasia) or the patient (in refusal of food). Moreover, a decision to commence (tube) feeding once a patient is so weak that they become incompetent is at odds with the judgement that Jehovah's witnesses carrying cards saying they do not want to receive blood products cannot be given transfusions – even if they are unconscious upon arrival at hospital.<sup>20</sup>

Whilst it cannot be denied that providing food is both culturally and morally symbolic, we are generally considered free to restrict our food intake or engage in gluttony as we like – however immoral or imprudent it is to do so. We might argue that those who seem intent on eating themselves to death have moral obligations to consider the needs of others. It may even be permissible to restrict their access to therapies whose effectiveness is undermined by their obesity, in favour of giving it to others who are more likely therefore to benefit. It is unlikely, however, that people who are either on the way to eating themselves to death, or who are likely not to receive the therapy they need to survive unless they stop over-eating, would or ought to be compelled by physical force to reduce their food intake.<sup>21</sup> It would be argued that they have to decide for themselves what to do and take responsibility for the consequences of the decisions they make. Once again, a distinction between the irrational and the incompetent is a pivotal one.

## ANOREXIA NERVOSA AND THE DECISION TO REFUSE FOOD

The condition which challenges these distinctions is anorexia nervosa where food is refused because the patient is completely obsessed with the idea of weight loss, or maintaining weight at a level incompatible with active life or even any life at all. Here the lack of distinction between providing food and therapy is even more marked because nutrition is very definitely part of the therapy required to restore the anorexic to 'health'.

Inverted commas around health are necessary here because anorexia nervosa is commonly, but often uncomfortably,

<sup>20</sup> See for instance the Canadian case *Malette v. Shulman* NW Ont CA (1009) 67 DLR (4th) 321.

<sup>21</sup> Though we may of course want to act if this behaviour was symptomatic of a mental disorder, which will be discussed shortly.

described as an illness – a mental illness. The ambivalence with which this categorisation is viewed by treating clinicians is very evident in Crisp's textbook *Anorexia Nervosa: Let me be*.<sup>22</sup> Crisp – widely recognised as an international expert on eating disorders – claims in the first chapter that in his opinion the condition is an illness. His theory is that anorexia is a psychological adaptive stance operating through biological mechanisms, as the sufferer tries either to avoid puberty or return to a pre-pubescent state.<sup>23</sup> Nevertheless, he almost invariably puts 'illness' in inverted commas when referring to anorexia and frequently compares it to alcoholism, another state that is only uncomfortably described as an illness.

The anorexic's determination to starve in the face of abundance is essentially seen as irrational – what ever psychological theory is used to explain this behaviour. As has already been indicated, whether it is a sufficiently irrational obsession to be categorised as a mental illness cannot be taken for granted, but even if it is, it is far from obvious that simply being classed as suffering from a mental illness is necessarily an indication that one is an incompetent individual. Nor is it obvious that anorexics refusing therapy are sufficiently irrational to be classed as incompetent to make decisions regarding their food intake.

There are two justifications for associating irrationality with incompetence in the case of anorexia. One is that the desire not to eat undermines an even stronger desire not to die. Another is that the desire not to eat might itself be an involuntary one, grounded in some other deeply held, but false, belief about their body image – usually that they are 'fat'.

It is interesting that although the irrational nature of their beliefs is often cited (alongside the desire to prevent them from dying) as a reason to overrule their refusal of food, working *with* this irrational belief is also perceived to be a valuable clinical option. For instance, Crisp writes:

'... a statement that he (the therapist) agrees that the patient is probably better off, all things considered, remaining anorexic, can be the most helpful and often totally new experience for the anorexic. She can approach the task of

<sup>22</sup> Crisp, *Anorexia Nervosa: Let me be*.

<sup>23</sup> This is, of course, only one view about the origins of the disorder. For an excellent critique of Crisp and outlines and critiques of other theories, see Morag MacSween *Anorexic Bodies*, (Routledge, London and New York, 1996), Chapters Two and Three.

limited weight gain with much more confidence under such circumstances.'<sup>24</sup>

This suggests that therapists *are* prepared to work within the anorexic's frame of reference, *provided* that the anorexic is making decisions, which are life-promoting rather than decisions that are likely to result in her death. Of course, it is rational for the therapist to do this because it achieves his aim of preventing his patient's death. This does not, however, make the anorexic's beliefs any more rational. Accordingly, either the relationship is still one of the clinician's proxy determination of the best therapy for his patient (her wishes just happen to coincide with the therapy he has chosen for her); or, if the patient is considered to be competent to decide for herself, she is only *as* competent as she was when she decided to refuse food<sup>25</sup> – which makes any previous decision to over-ride her wishes and force-feed her highly paternalistic and even a battery, however well motivated. There is always a danger in clinical relationships that competence is more likely to be questioned when the patient disagrees with the judgement of the clinician. This questioning itself highlights the ease with which assessments about a patient's competence can be muddled by disagreements over the relative value of deep-seated beliefs.<sup>26</sup>

It is at this point that the clinical management of eating disorders begins to challenge the established view that competent refusals of consent must be respected. Let us return to one example and introduce yet another. Earlier, the point was made that it would be deemed unacceptable for clinicians to forcibly prevent from eating those whose over-eating was life-threatening. One reason for this is that over-eating is not considered to be a mental disorder. Yet, neither is the vast majority of under-eating – namely that which is done for the sake of current fashion and in conformity with current trends about body image and healthy living. Anorexia nervosa differs from this kind of under-eating in two important respects.

<sup>24</sup> Crisp, *Anorexia Nervosa: Let me be*, p. 146.

<sup>25</sup> Competent in a general sense. I do not, of course, mean an incompetent refusal of food on the point of near death. A patient who has been force-fed under a section, who is released from the section and then requests that this cycle is not repeated would qualify for the kind of consideration I am suggesting here.

<sup>26</sup> There are many examples of this in practice, particularly where patients refuse life-saving therapy. The issue is discussed in Heather Draper, 'Consent and Midwifery' in ed. Frith, L. *Ethics and Midwifery* (Butterworth Heinemann, Oxford, 1994). pp. 17–33 and Heather Draper, 'Women, reproductive responsibilities and forced caesareans', *Journal of Medical Ethics*, 22, 6 (1996), pp. 327–333.

First, the diagnosis is usually only made once the under-eating threatens life and health. Second, it is believed that the compulsion not to eat is somehow involuntary or beyond the control of the sufferer. If this is the case, then there are good grounds for supposing that in regard to eating, sufferers from anorexia are not competent. There is no one, universal explanation for this disorder but it is often associated with other psychological problems such as low self-esteem, a sense of having no control over one's lives, or a history of sexual abuse. But the same could be said of at least some of those who over-eat, and if this over-eating puts their lives in jeopardy perhaps compulsory therapy could also be ordered in these cases too. A reluctance to extend still further the influence of psychiatry into eating habits is understandable. But does the unwillingness to section patients who endanger their lives through over-eating owe more to moral disapproval of gluttony than it does to an absence of evidence that people who are over-weight also have psychological problems which can account for their eating disorders? If so, then it is the conflict of relative values which accounts for how competence to control eating is assessed rather than the extent to which the activity is self-harming or involuntary.

The second example concerns those women who refuse to undergo radical breast surgery when they are diagnosed with breast cancer, because they consider that their breasts are so integral to their identity and/or quality of life that they would rather die with their breasts intact, than live without them. This is a view that attracts a great deal of sympathy, despite the fact that it seems irrational to give greater weight to one's body image than to one's life expectancy. But provided that she is competent and understands the dangers of refusing to consent, such a patient would never be compelled to undergo surgery. In this case, competence and irrationality are clearly differentiated.

But what of the sufferer from anorexia who refuses therapy, not because she thinks that her condition is not life-threatening, nor because she refuses to accept that she has a problem at all, but because for her too the burden of therapy and the side-effects of successful therapy – in terms of the body with which she will be left – are such that she prefers to take her chances with death? Such a sufferer would not be a typical case (any more than a woman who refuses surgery for breast cancer is would). However, what we need to be mindful of at this point is that some sufferers from anorexia nervosa are never cured, not even to the extent that they are able to live with their disorder by maintaining an abnormally low but constant, life-sustaining

body weight.<sup>27</sup> Granted that the received wisdom is that of an illness with a natural cycle of anywhere between one and eight years, under discussion here someone who has endured a decade or more of repeated painful weight loss and traumatic weight gain. The stress of living with anorexia nervosa prompted Crisp to write:

(m)any anorexics feel constantly like alcoholics, that they are just one step away from disaster. When suicide occurs it is often within this context. The individual is seeking relief from the endless terror and the exhaustion of a battle to maintain her position.<sup>28</sup>

Crisp acknowledges that the tension between the desire to eat and fear of the consequences of eating is a constant battle; one that can leave the sufferer from anorexia feeling so battle-weary that death becomes a viable and preferred option. If this is true for those sufferers from anorexia who decide to take their own lives, why can it not also be true for some of those sufferers from anorexia who refuse the therapy which will save their lives? Indeed, this seems to have been the decision made by Catherine Dunbar. In her account of Catherine's death, her mother describes how Catherine eventually found that she could not bear what her anorexia was doing to her, and couldn't live with any weight gain.<sup>29</sup> It is clear from this account that Catherine made a positive decision to die and only gained inner peace when others accepted this decision.

It is possible that some of those who over-eat do not do so voluntarily, over-eating could be a symptom of an underlying mental disorder. If so, then if preventing over-eating extends life long enough for this mental disorder to be treated effectively, forcible prevention may be justified and we are doing an injustice to sufferers when we do not take this possibility into account. Equally, some refusals of consent by sufferers from anorexia may actually be voluntary. It was noted earlier that many sufferers are not broadly incompetent. Granted that broad competence is intact,<sup>30</sup> we should be open

<sup>27</sup> Statistics for recovery vary. Lang, *The Harvard Medical Letter* cites a recovery rate of between 50–70% over ten years. E. D. Eckert, *et al* 'Ten year follow-up of anorexia nervosa: clinical course and outcome', *Psychological Medicine*, 25 (1995), pp. 143–156 suggest a 24% full recovery rate and just under 50% benign outcome. Obviously, taken together these sources suggest a failure rate of between 25–50% over ten years.

<sup>28</sup> Crisp, *Anorexia Nervosa: Let me be*, p. 81.

<sup>29</sup> M. Dunbar, *Catherine: A Tragic Life*, (Penguin, London, 1986).

<sup>30</sup> Which, again, would exclude those on the point of starving to death.

to the possibility that sufferers are actually as competent as anyone else to make decisions about the quality of their lives, and to assess the relative value of their lives in the light of its quality. For this reason, it is proposed that it may be wrong, as well as unlawful, to force patients to comply with therapy simply because they are anorexic.

It is undoubtedly awful to watch someone – possibly a young someone – die when they can so easily be saved. However, if justice is to be given to those sufferers who can neither live with their anorexia nor live without it, we must listen carefully to their refusals of therapy. The first step on this road is to accept that at least some sufferers from anorexia may be competent to refuse therapy – even if this is only a tiny minority. To do this we will have to listen to the reasons that they give for their refusal, not to determine whether or not these reasons are rational per se, but to hear whether these reasons reflect the burden that life with anorexia and therapy has become. We need to bear in mind that there is a difference between saving the life of a sufferer and curing them of their anorexia. Whilst feeding may be life-saving, it does nothing for the underlying condition – indeed it may even worsen it. Accordingly, we may also have to be open to the possibility that some sufferers from anorexia will never be cured, and that offering palliative care in such cases should not be dismissed as collusion with a mental illness. Rather it should be seen as offering the same services to incurable anorexics as are available to others who cannot be cured.

There is a wider danger in rejecting the possibility that some refusals of therapy by sufferers from anorexia are actually about quality of life and not involuntary refusals of food. This danger is that of weakening of the distinction between passive euthanasia and competent refusal of life saving therapy. If we exclude the possibility of a competent refusal being made for reasons which we cannot endorse – which I am suggesting may be happening in a minority of anorexia cases – there is a danger that a refusal of life-prolonging therapy will need to become as convincing to a physician as a request for passive euthanasia needs to be. Respecting a patient's autonomy is not simply about letting her make some decisions, or even all decisions. It is also about accepting that it is the patient who is responsible for the consequences of her decisions, and not the person who records this refusal of consent in the patient's medical notes.

*Centre for Biomedical Ethics  
The University of Birmingham*