

A Jurisprudence of Ambivalence

Three Legal Fictions Concerning Death and Dying

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—INTRODUCTION

The advent of artificial ventilation and other life-sustaining technologies has produced death scenes of a particular sort. When a person would rather die than endure these treatments, the death scene may be the subject of prior discussion, debate or demand. A person may insist that they no longer wish to live if there is no hope for improvement, or that they want doctors to remove the technology upon which their continued life depends. They might even request that withdrawal occur in one way rather than another. Accordingly, these death scenes usually require some planning, and they are necessarily contingent on the involvement and co-operation of others.

This article will explore the death scene following treatment withdrawal, drawing upon two cases: *Ms B. v An NHS Hospital Trust*¹ and *Brightwater Care Group (Inc.) v Rossiter*.² The former is the leading English decision in which a conscious patient's choice to die was upheld. The latter is the first such decision of an Australian supreme court.³ Both cases concerned middle-aged individuals who had

suffered serious injuries that rendered them quadriplegic, though neither was terminally ill or dying. Both claimants were dependent on technology to support their basic life functions: Ms B. required permanent ventilation and Mr Rossiter could not ingest food and water other than via a tube inserted into his stomach.⁴ Both individuals found their quality of life unacceptable and had decided that they no longer wished to continue living.⁵

Although these cases were determined in accordance with well-established principles concerning consent to medical treatment,⁶ they were novel in important respects. Unlike earlier decisions concerning advance directives, these cases each involved a subject who was expressing a present, conscious desire to die and who was, through law, seeking to establish some agency in constructing their own death scene. Ms B. wanted to be sedated and to have her ventilator switched off so that she would die quickly and without awareness. Although Mr Rossiter faced a more protracted death from starvation, he requested that the PEG (percutaneous endoscopic gastronomy) tube remain in place so that he could still receive medication dissolved in water after feeding and hydration ceased. Both claimants requested that their death be brought about in quite specific ways, a feature which brings them into close proximity with culpable deaths such as assisted suicide or mercy killing.⁷ In this respect, the cases provide an opportunity to explore whether the law's account of these deaths as materially different from unlawful deaths, can withstand scrutiny.

This article identifies three legal premises that have been crucial in distinguishing the choice to die in the context of treatment withdrawal from unlawful assistance to die. These are: (i) a competent patient can refuse medical treatment for any or no reason even if it means they will die; (ii) the doctor's removal of life-supporting technology does not entail responsibility for the resulting death; and (iii) such deaths are natural deaths. I argue that these premises constitute 'fictions'⁸ or pretences in the sense that they do not reflect the complex realities associated with these death scenes. They do not, for instance, acknowledge the fear and uncertainty felt by patients who are unwilling to go on in the face of unyielding disability, the ontological anxiety produced by abject embodiment, the ambivalence experienced by some doctors about their agency in these deaths and the human orchestration involved in producing a 'natural' death. Nor do they

capture the myriad ways in which law must negotiate or repress these complexities. The argument developed here is that when patients and doctors disagree about whether and how death should occur in the treatment withdrawal context, the legal premises become increasingly strained and the conceptual space created by law to distance these deaths from 'culpable' deaths is threatened. It is in these moments of dispute that the fictions are exposed and law's underlying ambivalence about the choice to die revealed.

—FICTION 1: A COMPETENT PATIENT CAN REFUSE MEDICAL TREATMENT FOR ANY REASON OR NO REASON, EVEN IF IT MEANS THEY WILL DIE

Central to this field of legal decision-making is a conception of personhood that is closely aligned with the liberal philosophical conception of self.⁹ As Naffine explains, this legal person is 'the rational and therefore responsible human legal agent: the classic contractor ... the individual who possesses the plenitude of legal rights and responsibilities, the ideal legal actor'.¹⁰ The influence of this construction of personhood is immediately apparent in the guiding legal principle on treatment refusal, famously articulated by Lord Donaldson in *Re T (Adult: Refusal of Treatment)* a case concerning the refusal of a life-saving blood transfusion:¹¹

Prima facie every adult has the right and capacity to decide whether or not he will accept medical treatment, even if a refusal may risk permanent injury to his health or even lead to premature death. Furthermore, it matters not whether the reasons for the refusal were rational or irrational, unknown or even non-existent. This is so notwithstanding the very strong public interest in preserving the life and health of all citizens.¹²

Despite law's formal acknowledgment of the competent patient's right to refuse medical treatment, there seems to be a great deal of ambivalence about such decisions when they will lead to death. In neither *Ms B v An NHS Hospital Trust* nor *Brightwater Care Group (Inc) v Rossiter* did the court directly confront death. On the contrary, each court was careful to distance itself from the deaths, emphasising that its only role was to determine legal capacity of the claimants and the legal obligations of the health care providers.¹³ Indeed, death was held in abeyance. Butler Sloss P., for instance, observed that her decision left 'Ms B. with a future choice which she can consider freely now that she will be relieved of the burdens of

litigation'¹⁴ Martin CJ too seemed reluctant to see his decision as determinative of Mr Rossiter's death, stating that 'the question of whether or not [Mr Rossiter] repeats such an instruction after this ruling ... is entirely a matter for him. I would also observe that any such direction would not be irrevocable, and while he retains his capacities, could be revoked by him at any time'.¹⁵

Law's tentativeness about the decision to die is also expressed in more subtle and complex ways. In the field of medical decision-making, perhaps more so than most, the 'ideal legal actor' to which Naffine refers assumes a corporeal form. In *Brightwater Care Group (Inc) v Rossiter*, Martin CJ, affirming Lord Hoffman in *Airedale National Health Trust v Bland*, described the right to self-determination as 'being related to respect for the individual human being and in particular for his or her right to choose how he or she should live his or her life'.¹⁶ His Honour also acknowledged that the right encompasses the right 'to determine what shall be done with his own body'.¹⁷ The right 'to determine what shall be done with one's body' provides a clue to the role of embodiment in a conception of personhood that is otherwise silent on the matter. Thus, the rights-bearing legal person has a body, over which he assumes control and mastery. As Naffine observes: 'individuation and self containment are essential if the rational subject is to be free to act in ways which affect only his self: if he is to be fully capable of confining and containing the effects of his actions to himself and to no other'.¹⁸ Thus, 'the body must be carefully controlled for only then can [the legal person] transcend the limitations of his physiology ... to become an intelligent agent'.¹⁹

This conception of legal personhood has been criticised on the grounds that it implicitly assumes a privileged male embodiment and is thus exclusionary.²⁰ Indeed, this ontology can pose special problems in circumstances where, as here, it might be difficult to achieve an appropriate distance between self and body. As the claimant in *Re T (Adult: Refusal of Treatment)* discovered, it may not be sufficient to simply say no to unwanted medical treatment.²¹ Lord Donaldson's principle, it turns out, is subject to some fairly wide exceptions. For instance, an individual's 'will' might be adversely affected by their corporeality (for example, if in pain, affected by drugs or fatigue) or by the overbearing will of another. In such cases, the principle of self-determination will not apply. Where there is doubt, courts will need to be satisfied that the subject seeking to assert their rights is appropriately individuated

and self-contained. It may need to ask: is their capacity eroded by pain, fatigue or other factors?²² Was the decision really theirs?²³ Did they mean to choose this way?²⁴ Any of these factors might disqualify a treatment refusal by casting doubt on an individual's competence, strength of will or intentions. Indeed, the Court of Appeal in *Re T* held that if there is any doubt about these matters 'that doubt falls to be resolved in favour of the preservation of life, for if the individual is to override the public interest he must do so in clear terms'.²⁵

The breadth of these exceptions constitute one of the most obvious ways in which Lord Donaldson's principle does not fully capture the realities associated with treatment refusal. Another is the intense judicial scrutiny of the choice to die. In *Ms B's* case, the court was meticulous in its approach to Ms B.'s capacity and, in particular, to the question of whether she herself felt ambivalent about her decision to die. In *Rossiter's* case, the court imposed an additional and novel requirement of 'informed refusal' before his decision could be acted upon.

The choice to die must bear no trace of ambivalence and must be adequately informed

In *Ms B v An NHS Hospital Trust*, the principal legal issue was whether Ms B. had capacity to request the removal of her ventilator. Although the common law of England and Wales presumes that adults have capacity, that presumption may be displaced by evidence that the person is unable to: (i) comprehend and retain the information which is material to the decision; (ii) apprehend the likely consequences of having or not having the treatment in question; or (iii) weigh the information in the balance as part of the process of arriving at a decision.²⁶ As Morgan and Veitch point out, the final requirement of the test for capacity sits somewhat uneasily with the principle that treatment can be refused for no reason at all.²⁷ They argue that it is difficult to rationalise a requirement that the claimant weigh and balance information and, at the same time, assert that no reasons are necessary.²⁸ It is suggested that, to the extent that this apparent contradiction provides some flexibility in the construction of the evidence of capacity, it constitutes further evidence of the law's ambivalence.

The evidence of incapacity in *Ms B's* case focused on Ms B.'s apparent ambivalence about her choice to die. The hospital claimed that Ms B. was ambivalent, firstly, because when told that the hospital would not be acting on her

request to remove ventilation, she expressed a sense of relief and, secondly, because she agreed to have bronchoscopies performed in order to preserve her life. Ms B., on the other hand, explained that she did 'have some sense of relief, but it was not the sort of relief like, "I am really glad to be alive" it was a sort of relief that I had a very difficult task ahead of me'.²⁹ In other words, although Ms B. wished to be dead, she was ambivalent about dying:

I was relieved to some extent by the fact that I would not have to deal with the undeniably stressful and difficult questions of saying goodbye to my friends and family. Although it is true that I felt some sense of relief, at no stage did I feel that I either regretted my previous decision or wished to change my mind.³⁰

In addition, hospital witness Mr G. testified that Ms B. had sometimes expressed gladness to be alive and at other times wished for the ventilator to be removed. He felt concerned 'that her wish to have the ventilator switched off stems not so much from a wish to be dead, as from her wish to be free from all that surrounds her current condition'.³¹ He had observed patients in similar situations change their minds about dying and argued that she was unable to give informed refusal of ventilation without personal experience of what might be achieved were she to commit to spinal rehabilitation. The court emphatically rejected this approach as 'impractical'³² concluding that neither her vacillation, nor her relief, justified a finding of incapacity as 'the ambivalence [did not] genuinely strike at the root of the mental capacity of the patient'.³³

Although the court construed the evidence as being insufficient to displace the presumption of capacity, Morgan and Veitch observe that 'the overall impression given by the judge was that Ms B. had reached certain unspecified standards of character and persuasiveness that made her deserving of having her decision upheld'.³⁴ The court considered Ms B. to be 'an exceptionally impressive witness' who 'appears ... to demonstrate a very high standard of mental competence, intelligence and ability'.³⁵ Butler-Sloss P. drew attention to Ms B.'s clarity of expression, the considerable research she had undertaken about her condition, and her high level of insight into the difficulties her decision was causing those around her.³⁶ In short, Ms B. was able to transcend her physical limitations to construct a determined, rational and desiring self.

Similar observations can be made of the manner in which the choice was constructed in *Rossiter's* case. Two medical experts testified that Mr Rossiter was capable of making decisions about his medical treatment. His doctor, Dr Bernstead, observed that he 'had the capacity to comprehend and retain information given to him in relation to his treatment, and has the capacity to weigh up that information and bring other factors and considerations into account to arrive at an informed decision'.³⁷ There was also evidence from a clinical neuropsychologist that Mr Rossiter 'was capable of making reasoned decisions about his health and safety, and in particular was capable of making decisions in respect of his future medical treatment after weighing up alternative options, and was capable of expressing reasons for the decisions he made in that respect'.³⁸ In addition, this witness testified that:

Mr Rossiter unequivocally demonstrated that he had understood the consequences of withholding the provision of nutrition and hydration through the PEG, and displayed insight into the consequences of that decision.³⁹

The court focused on Mr Rossiter's mental capacity to 'control his own destiny' despite his obvious physical incapacities.⁴⁰ Unlike Ms B., he did not express any fears about how he would die. On this issue, he was relatively matter of fact:

Q: Do you understand it would be potentially painful?

A: I would have painkillers ...

Q: Yes. Do you understand that if medical staff stop feeding you through the tube, that you will eventually die?

A: Yes.

Q: And is that something you want?

A: Yes. ⁴¹

Although Mr Rossiter testified to a general awareness that he would die a long and painful death from starvation, the court was not satisfied that he had been sufficiently informed 'of the precise aspects and effects of the physiological deterioration which will occur during the process of starvation'.⁴² Acknowledging that a requirement of 'informed refusal' had been rejected by *Hunter and New*

*England Area Health Service v A*⁴³ the court distinguished that authority on the grounds that:

The circumstances of this case are quite different. Mr Rossiter has the capacity to receive and consider information he is given and to make informed decisions after weighing that information. Also relevant is the fact that Brightwater have assumed responsibility for providing nutrition and hydration through the PEG for quite some time now, so the question is whether there should be a change in that regime.⁴⁴

Curiously, the court gave no guidance on how Mr Rossiter's understanding about his death was deficient. In particular, would the duty to provide 'full information with respect to the consequences of any decision he might make'⁴⁵ encompass information and advice about how his life could be improved (as Mr G. had unsuccessfully argued in Ms B.'s case) as well as how it could be ended? Whatever the case, the effect of this is to impose a different standard where the individual is conscious and therefore capable of receiving further information about how they will die. Such a requirement also ensures that any individual who expresses a wish to die will have to confront their own death scene and, moreover, to embrace it in all its specificity before their decision to withdraw treatment can be respected.

In short, a finding that Ms B. and Mr Rossiter were capable of making the choice to die depended in part on their success in constructing themselves as sovereign agents, unaffected by the will of others or their embodiment, and in possession of adequate information to make their choice. To achieve this, traces of ambivalence, ignorance and despair needed to be suppressed or minimised, for only then could each claimant approximate an appropriate subject of legal rights.

The paradox of abject embodiment

Although the law's ambivalence about the decision to die was overcome in part by the claimants' insistence that they were self-determining agents whose decisions the law was duty-bound to respect, there were other important factors at play. Chief among them was law's ambivalence about seriously disabling embodiment.⁴⁶ Intriguingly, and despite any formal legal requirement to provide 'reasons' for their treatment refusals, both courts heard lengthy testimony from Ms B. and Mr Rossiter

about their level of disability. Both claimants both spoke to the ways in which their bodily boundaries had broken down and how they could no longer exercise any control over them.

In constructing an intelligible account of her decision to die, Ms B. invoked an abject body, vulnerable and open, a space of suffering and violation.⁴⁷ As Waskul and van der Riet point out, the abject body not only violates biological boundaries—it also violates normative ones.⁴⁸ It threatens the very ‘accomplishment and maintenance of dignified selfhood’.⁴⁹ Indeed, Ms B. testified to her unbearable suffering in precisely these terms, naming the totality and intolerability of her dependence,⁵⁰ her lack of a supportive family and her fears about being abandoned to a nursing home.⁵¹ She explained that she had:

refused the specialist clinic because weaning is essentially a long term treatment for patients who want to live without ventilation. That is not what I want as it has no positive benefits for me given my level of disability.⁵²

Through these statements, Ms B. rather deftly ‘contrasts independent rational decision-making with an embodied construction of childlike dependence’.⁵³ Although her doctors attempted to challenge this negative self-assessment and entreated Ms B. to give rehabilitation a try before deciding to withdraw ventilation,⁵⁴ the court was not inclined to cavil with Ms B.’s self-assessment. Indeed, the court seemed unable to respond to Ms B.’s negative assessment other than to say that ‘one must allow for those as severely disabled as Ms B., for some of whom life in that condition may be worse than death’.⁵⁵

Mr Rossiter also provided reasons for his decision, again despite any strict legal requirement to do so. The court heard detailed testimony about the indignities of his present condition:

I am unable to undertake any basic human functions, including but not limited to: I am unable to talk without a tracheostomy; I am unable to clear the phlegm from my throat to enable me to speak through the tracheostomy ... I am unable to blow my nose, I am unable to walk or move my body at all, apart from involuntary spasmodic movements; I am unable to wipe the tears from my eyes. Nursing staff are required to wipe the stools from my bottom ... I require a catheter or uridome by way of a

condom placed over my penis to pass urine. The urine is collected in a bag ... the uridome frequently slips off soiling both me and the bed linen. This requires frequent changing of the bed linen. Nursing staff roll me from side to side every six hours or so to prevent bedsores...⁵⁶

Like Ms B., Mr Rossiter called attention to the tremendous suffering entailed by his unbounded and disordered body. His inability to contain and manage his bodily fluids and excrement were, it would seem, engaged as particularly potent signifiers of his abjection.⁵⁷ They, too, seem intended to convey, not only the grotesqueness of his physical condition, but also his symbolic reduction to an ‘infantile “non-person” or “open person” status’.⁵⁸

Arguably, these personal claims about the catastrophic nature and effect of the claimant’s disabilities play a crucial persuasive role. As Kristeva explains, the object is not simply an absence of cleanliness or health, but an absence of boundary.⁵⁹ This is an absence that disturbs ‘identity, system, order’ and, in turn, provokes horror, both in those who experience and witness it.⁶⁰ In keeping with this insight, Koch observes that where disabled embodiment ‘is sufficiently severe, the person is assumed to be diminished, lessened both existentially and as a member of the social constituency we share’.⁶¹ It might be objected that, far from being diminished as subjects, Mr Rossiter and Ms B. were ultimately granted the subject status necessary to have their legal rights respected. However, it seems likely that this occurred because of, rather than in spite of, their abject embodiment. Their subjective assessment of the nature and extent of their disabilities seem calculated to render intelligible, and perhaps even rational, their choice to die. That these assessments were accepted without significant challenge arguably reinforces the conception of disability as a diminished state—one that may even be less desirable than death itself.⁶² At the very least, it is apparent that both cases engage an exceedingly complex set of symbolic negotiations around selfhood, disabled embodiment and death that converge around the fiction of the rational choosing agent. Indeed, there appears to be paradox at work in these cases. On the one hand, embodiment may be configured as a potential threat to rationality, while, on the other, it may be configured as evidence of a diminished personhood that can justify the desire to die.

Where a competent patient objects to the continuing use of life support, a doctor is under a legal obligation to cease treatment on the grounds that continuing treatment would constitute a battery. However, where the cessation of treatment will result in a patient's death, a question arises as to whether the doctor might face criminal responsibility for causing that death. The general principle is that if there is no duty to treat, the removal of life support is construed as an omission for which there is no legal liability. It is clear however that the common law of England and Wales acknowledges the pretence of construing treatment withdrawal as an omission. As Lord Goff has observed:

the doctor's conduct in discontinuing life support can properly be categorised as an omission. It is true that it may be difficult to describe what the doctor actually does as an omission, for example where he takes some positive step to bring the life support to an end. But discontinuation of life support is, for present purposes, no different from not initiating life support in the first place. In each case, the doctor is simply allowing his patient to die in the sense that he is desisting from taking a step which might, in certain circumstances, prevent his patient from dying as a result of his pre-existing condition.⁶³

In *Rossiter's* case, the question of criminal responsibility fell to be considered in light of the provisions of the *Criminal Code* (WA). The doctors were concerned that the Code might alter the common law such that their agreement to stop feeding and hydration other than for the delivery of drugs might breach the statutory duty imposed by s262 of the Code (the duty imposed on those having the charge of another to provide the necessaries of life) and thus be treated as the cause of death for the purposes of s270 or s273. Even if that were not the case, the doctors were concerned that administering drugs to keep Mr Rossiter comfortable after feeding ceased, especially in light of the fact that he had decided to refuse treatment so that he could die, might be construed as assisting a suicide.⁶⁴

The court interpreted these provisions consistently with the common law position on treatment withdrawal. Thus, the doctors were not under a statutory duty to provide the necessaries of life to a competent person who refused them. Section 262 did not apply because Mr Rossiter was not, relevantly, 'under their

charge'.⁶⁵ Even if that were not the case, the court held that s259(2) would provide a full defence to any charge. Section 259(2) provides that a person is not criminally responsible for ceasing to administer medical treatment if it is reasonable, having regard to the patient's state at the time and to all the circumstances. It was held that:

Plainly, the phrase 'all the circumstances of the case' is quite broad enough to include the informed decision of a mentally competent patient. Having regard to the strength of the common law principle of self-determination ... it is clearly 'reasonable' to act in accordance with the informed decision of a mentally competent patient who refuses to consent to medical treatment.⁶⁶

The construction of the removal of life support as an omission is critical in distinguishing these death scenes from unlawful death scenes in which 'active' steps are taken to end life on request or where assistance is given to enable a patient to commit suicide. The law maintains this distinction despite the fact that all of these scenes share the common feature that an autonomous patient wishes to die. In *Rossiter's* case, the court was emphatic:

It is important I think to emphasise at the outset what this case is not about. It is not about euthanasia. Nor is it about physicians providing lethal treatments to patients who wish to die. Nor is it about the right to life or even the right to death ...⁶⁷

Nevertheless, as Lord Mustill acknowledged in *Bland*, the points of differentiation between lawful treatment withdrawal and culpable deaths can be difficult to justify. His Lordship observes:

The conclusion that the declarations can be upheld depends crucially on a distinction drawn by the criminal law between acts and omissions, and carries with it inescapably a distinction between, on the one hand what is often called "mercy-killing", where active steps are taken in a medical context to terminate the life of a suffering patient, and a situation such as the present where the proposed conduct has the aim for equally humane reasons of terminating the life of Anthony Bland by withholding from him the basic necessities of life. The acute unease which I feel about adopting this way through the legal and ethical maze is I believe due in an important part to the sensation that however much the terminologies may differ, the

ethical status of the two courses of action is for all relevant purposes indistinguishable. By dismissing this appeal I fear that your Lordships' House may only emphasise the distortions of a legal structure which is already both morally and intellectually misshapen. Still, the law is there and we must take it as it stands.⁶⁸

The shortcomings of the act/omission distinction are brought into sharper focus when doctors and patients disagree about treatment withdrawal. Although this did not occur in Rossiter's case because doctors were non-committal about his decision, it was quite the opposite in Ms B.'s case. When such disputes occur, the construction of these scenes as scenes of 'natural' death, and therefore beyond the agency of the doctors concerned, may be challenged by doctors who are unsure, unable or unwilling to understand the autonomy of the patient as determinative, or cannot otherwise characterise their role in the death as negligible.

The technology is keeping the patient alive

In *Ms B.*'s case, the court repeatedly emphasised the fact that the artificial ventilation was 'keeping her alive'.⁶⁹ Implicit in this characterisation is the notion that Ms B. is only alive because the machines have interrupted a natural course of events which would have otherwise lead to her death. Here the law accepts that life supported by (certain) technologies is already contingent, with the result that the removal of technology is characterised as a return to a pre-intervention 'natural' state of being. Within this construction, the removal of life support 'counts as the annulment of effect and responsibility, not as new or secondary effect engendering new responsibilities'.⁷⁰ This has the effect of rendering the return to a natural state of affairs as reassuringly 'outside human direction'.⁷¹ Hopkins explains:

The discursive space thus created is centrally a moral space for, perceived as an area where humans are not acting, it is also therefore an area where human moral responsibility cannot obtain...⁷²

Hopkins criticises the natural/artificial binary upon which this reasoning relies as being inadequate to explain the moral differentiation at work.⁷³ Using the pacemaker to illustrate, he suggests that despite being an entirely 'artificial' organ, and one which is required because of the person's underlying illness, few people would construe turning off someone's pacemaker to allow the underlying 'natural'

disease to take its course, as anything less than murder.⁷⁴ This is, he argues, because it is not the technology itself that determines our ethical stance toward its removal, it is, rather, the futility of the life being preserved.⁷⁵ He argues that:

Moralists are inconsistent in their claim that in turning off machines we only return patients to their natural states, resulting in deaths we did not cause and cannot be culpable for. It is just that in some particular cases, where we think the patient is better off unambiguously dead but are not willing to bear the moral taint of having killed, that the appeal to a natural death gives us a way out. It allows us to think that when we remove the machines necessary for living, we are not killing.⁷⁶

In Hopkins' view, withdrawal of treatment where death will result is killing but it is justifiable. Importantly, it is our sense of the futility of treatment, rather than the defeasibility of technology, that makes it so. The corollary of this argument is that there is no justifiable reason to deny assisting to die those who wish to but are not dependent on life support. As he concludes:

if we are cruel in refusing to let nature free patients from the trap of technology, we are both cruel and conceptually blind when we refuse to let technology free patients from the trap of nature.⁷⁷

Another corollary of Hopkins' analysis is that treatment withdrawal leading to death might be construed as killing in circumstances where treatment is not thought to be futile. Indeed, this was a crucial point of distinction between the doctors and Ms B. Ms B. testified that she found 'the idea of living like this intolerable',⁷⁸ and that she simply could not 'accept [her]self as disabled and dependent'.⁷⁹ When questioned about the prospect of rehabilitation, she said:

It offers me no real opportunity to recover physically that, in actual fact, it will be more teaching me to live with my disability and to make use of the technologies available and that sort of thing, working with the carers. But, actually, I will not recover in any way. That is not acceptable to me.⁸⁰

It is not too much of a stretch to say that Ms B. found the treatment that she was receiving futile because she did not accept her life as it was and would be into the future. In contrast, Ms B.'s doctors emphasised the benefits of rehabilitation and the full range of environmental systems that could assist her. As such, they did not think

her better off dead and therefore struggled to understand the immediate withdrawal of ventilation as letting die rather than killing.

The doctor has no agency

Although it is clear that the law does not usually regard the removal of treatment as killing, the doctors in *Ms B.*'s case were nevertheless unsettled by their sense of responsibility for the anticipated death of their patient. They simply refused to facilitate the immediate withdrawal of ventilation in accordance with her wishes (although, as I will explore further in the next section, they were prepared to engage a phased withdrawal of ventilation which would also almost certainly lead to her death). This seems to fit with Burt's claim that although we may 'parrot the language of rational choice in comparing our fears about death with our fears about continued life in the face of illness or disability',⁸¹ we cannot completely bury our sense of death's 'wrongness'.⁸² His argument, that most people cannot resist a 'moralized understanding' of death,⁸³ is supported by the attitudes of *Ms B.*'s doctors. Dr R. gave evidence that 'if the ventilator were switched off, the end would be in a few hours. Immediate withdrawal would cause her death'.⁸⁴ The lead clinician, Dr C., 'felt like she was being asked to kill *Ms B.*'⁸⁵ As Butler-Sloss P. noted:

both the treating clinicians were deeply distressed by the dilemma which had faced them over the year that *Ms B.* has spent in the ICU. They knew her well and respected and liked her. They considered her competent to make decisions about her medical treatment. They could not, however, bring themselves to contemplate that they should be part of bringing *B.*'s life to an end by the dramatic (my word) step of turning off the ventilator.⁸⁶

The construction of immediate withdrawal of ventilation as 'killing' raises an interesting challenge to the idea that patient autonomy could provide an adequate justification for *Ms B.*'s death. From the perspective of *Ms B.*'s doctors, her death did concern them, was contingent on their co-operation and, consequently, affected them also. In drawing attention to this, *Ms B.*'s doctors position another autonomous 'self' within the death scene. This other self is not merely an onlooker, but an active participant in the death scene. This poses a direct challenge to the fiction that the doctors exercise no agency and thus bear no responsibility for such deaths. This re-

construction of the death scene as engaging two autonomous selves—the patient and the doctor—also finds echoes in Mitchell’s research on physician commitment to end of life care. Mitchell observes that where the doctors in her study were faced with the request for euthanasia, ‘the seriousness of the request rendered the autonomy of the doctor in granting or refusing the request equal to the patient in making the request’.⁸⁷ Doctors who acceded to a request for euthanasia portrayed the decision as extremely difficult and often constructed the decision to assist as a ‘sacrifice’ (of autonomy) on their part, which was undertaken for the benefit of the patient.⁸⁸ Mitchell continues:

There is a sense here that the doctor is constructing another self involved in the decision-making. There is a professional self, a ‘physician’ who has responsibility in the caring relationship but there is another self, a ‘human being’ rendered vulnerable by the euthanasia request. This ‘vulnerable self’ now has needs that are on par with the patient’s needs and must have equal consideration in the decision-making.⁸⁹

The patient’s direction to switch off a ventilator may render the doctor vulnerable even where he or she supports the patient’s decision to refuse treatment. To draw on another example, physicians Edwards and Tolle were convinced of the legal and ethical acceptability of withdrawing the ventilator from their competent patient, though they nonetheless reported feeling like they were responsible for killing him. They described being ‘in the death scene’ in the following way:

We looked into the face of an alert man who we knew would soon die. Our more rational instincts told us that his disease, not us, would be the cause of his death. Deep feelings, on the other hand, were accusing us of causing his death. From deep within us, feelings were speaking to us, making accusations ‘You are really killing him, practicing active euthanasia, deceptively rationalizing with your intellects that there is a difference.’⁹⁰

Although these physicians had decided that the patient’s decision should be respected, being ‘in the scene’ clearly posed challenges that they had not anticipated. In the context of sudden interruption of respiration, the doctors struggled with the idea that they were merely withdrawing from their patient to allow nature to take its course. They worried about how much sedation to provide during the disconnection of the ventilator, a question they acknowledged as ‘difficult when the

goal is relief of suffering without deliberately inducing a respiratory arrest'.⁹¹ Nonetheless, it is clear that they needed to maintain a belief that the drugs they administered did not cause death:

We respected his right to refuse further life dependent on the ventilator. A heavy feeling of intense emotion consumed both of us as we slowly injected midazolam and morphine, watching the patient closely so we could produce the desired level of drowsiness ... we stood frozen as Mr Larson continued to take shallow but regular breaths. We felt some relief; at least we had not sedated the patient so heavily that this alone would cause his immediate death.⁹²

The distinction between inducing sufficient drowsiness to keep the patient comfortable while they die but not so much as to depress respiratory effort seems to be yet another expression of ambivalence about such death scenes and, at the very least, a subtle acknowledgment of their 'close proximity'⁹³ to culpable conduct.

—FICTION 3: DEATH FOLLOWING A DECISION TO REFUSE TREATMENT IS A NATURAL DEATH

As already considered, the law constructs the death scene of an individual who has decided to refuse continuing life support as a natural death; that is, a death that merely happens in the natural course of events rather than a death that is caused. The extent to which this representation will make sense in the context of a given death scene may be highly dependent on the individual patient, the nature of, and manner in which, the treatment is withdrawn and the dying trajectory that follows. In the cases under consideration, at least three possible death scenes were canvassed: Mr Rossiter would gradually slip away as a result of starvation; and Ms B. would either die relatively slowly from sepsis or chest infection following a phased withdrawal of ventilation or quickly and painlessly following an immediate withdrawal of ventilation.

Difficulties with the construction of a natural death may arise where the meaning ascribed to 'natural' is 'in accordance with nature' or otherwise 'free from calculation'. It is a distinctive feature of these deaths that they can seem optional rather than inevitable (in the sense that the patient could choose to remain alive on life support) and that death might even be highly orchestrated, involving choices that will determine the nature of the dying trajectory.

Orchestrating a 'natural' death scene

As Pool observes, 'natural' and 'unnatural' deaths are not fixed concepts but are, rather, highly contextual representations.⁹⁴ Thus, a heavily sedated death might be portrayed as natural by some doctors, but considered as unnatural by those who associate nature with non-intervention.⁹⁵ Despite these divergent interpretations, Pool points out there seems to be 'a general consensus that, at the very least, natural death can be said to consist of fading away peacefully and the end of a full life'.⁹⁶ Indeed, there are echoes of this sensibility in the manner in which the hospice movement constructs a 'good' death. This, as Seymour describes, embraces:

An ideology of personal knowledge, control and choice, conjoined with control of physical suffering by the judicious use of (preferably) 'low' technology clinical intervention in which the 'natural' course of dying is reclaimed from the threat of the vice like grip of more advanced 'high' technology interventions.⁹⁷

There is also some evidence that the 'fading away' aspect of a natural death is so central to this construction of death that doctors seek to replicate it even in highly technological environments. In her study of intensive care units, Harvey found that life support tends to be withdrawn gradually, in an 'attempt to regulate, routinise and produce a standard death'.⁹⁸ She argues that this standardisation of death serves two purposes: it allows time for the relatives to adjust to the fact that death is occurring; and it has the effect of making the death appear more 'natural' and less 'technologically' and clinically driven.⁹⁹ Death may then be 'presented as a less dramatic disjuncture', neither 'too abrupt or professionally induced'.¹⁰⁰

If a 'slow fading away' is a familiar feature of a natural death, Mr Rossiter's death scene would seem to pose less of a challenge to this representation. He would indeed 'slowly fade away' albeit as a result of his own choice. Ms B.'s chosen death scene (the immediate withdrawal of ventilation) was more challenging in this respect. It is arguable that her doctors were unable to reconcile the suddenness of the anticipated death with the representation of such as death as 'natural'. Tellingly, however, they were prepared to accept a compromise in which the ventilator could be withdrawn via a one-way weaning program. This involved a gradual reduction of the number of breaths supplied by the ventilator in the hope that the patient's lungs would, over a managed period, adapt to breathing independently. In a one-way

weaning program, the number of breaths are reduced gradually, but not increased again if the patient cannot manage at the reduced level. Sedation is given 'but not so as to depress respiration, unless clinically indicated'.¹⁰¹ Although the one-way weaning program offered the small possibility of Ms B. becoming independent of the ventilator, it was much more likely that it would in effect fail and Ms B. would die anyway.

The apparent contradiction between rejecting immediate, but not phased, withdrawal of ventilation indicates that the manner in which Ms B. died (rather than her death *per se*) was significant. With immediate withdrawal, death would be temporally connected to the act of switching off the machine, leaving little ambiguity in the doctor's minds about the cause of death. Moreover, because death would occur with absolute certainty, this would leave no room to hope for unexpected progress or, perhaps even, a change of heart on Ms B.'s part. Finally, immediate withdrawal would leave little space for locating responsibility for the death elsewhere—for example, her underlying illness or some other 'natural' event, such as a chest infection. In this sense, phased withdrawal of ventilation was better adapted to give expression to the doctor's ambivalence and to simulate a more natural dying trajectory. As the court acknowledged, the 'one-way weaning process appears to have been designed to help the treating clinicians and the other carers and not in any way designed to help Ms B.'¹⁰²

Choosing a death scene

Both Ms B. and Mr Rossiter were prepared to embrace death, but neither was willing to leave the question of how they would die to the doctors alone. Seymour observes that the characterisation of a death as a 'natural' death can still occur in the context of the removal of technology, provided that the technology delivers outcomes that the companions of the dying person expected and which seemed to 'fit' with the wider context of the dying person's life.¹⁰³ In other words, 'it is perceptions of the meaning of technology, rather than its simple minimisation or absence, that determines representations of death in highly technological environments'.¹⁰⁴ This raises an interesting legal question: to what extent does the right to refuse medical treatment encompass some measure of control (where choices exist) over the subsequent dying process?

It will be recalled that Mr Rossiter did not want all food and hydration to cease, nor did he want the PEG tube removed. The PEG tube would remain in place so that he could receive pain relief via that route. Like Ms B., Mr Rossiter was able to imagine and describe his last moments and to make requests about how he would like them to pass. In his evidence, Mr Rossiter stated:

I would like to say that pain-killers could make me drowsy and I would like to be made drowsy in my final moments so that the time could pass more quickly and I would like to watch Foxtel on the television to pass the time.¹⁰⁵

The issue of appropriately situating the withdrawal of treatment against the legal framework for determining responsibility arose in *Rossiter's* case because the doctors were concerned that the legislative protection accorded to palliative care (s259(1) and (2) of the *Criminal Code* (WA)) might not apply if the situation giving rise to palliative care was brought about by the decision of the patient. Specifically, they were concerned that administering drugs to keep Mr Rossiter comfortable after feeding ceased, especially in light of the fact that he had decided to refuse treatment so that he could die, might be construed as assisting a suicide. As the doctors argued:

The scope of the notion of aiding a person in killing himself or herself is uncertain ... it may ... we fear ... extend to someone who provides relief from pain for the purpose of enabling someone to ease their passage ... [we seek the declaration on the apprehension that] somebody who, knowing of Mr Rossiter's desire not to live, if ceasing to feed him is properly construed as enabling him to die or indeed enabling him to kill himself, easing his pain as he does so could be seen as aiding that process.¹⁰⁶

In raising this argument, the doctors called attention both to the tenuousness of the act/omission distinction and the orchestration involved in this death scene. Unfortunately, the court did not engage with this complexity except to reiterate that although the administration of medication for the purpose of 'causing or hastening death' would be unlawful:

the legal rights and obligations relating to the provision of palliative care are unaffected by the circumstance that the occasion for the provision of that care comes about as a consequence of Mr Rossiter's withdrawal of consent to the ... medical treatment.¹⁰⁷

The 'choices' involved in regulating death were more stark in Ms B.'s case. As mentioned, doctors were prepared to countenance a simulation of a 'natural' death by phased withdrawal and a slow fading away by reason of infection or sepsis. Ms B. however, constructed a different death scene. She did not want to die in this way. For her, only the immediate withdrawal of technology with sedation would produce a dignified death:

My concern is that I would have a very long and uncomfortable, possibly painful passage ... [when ventilation became inadequate] I would then develop a chest infection and, possibly, other complications and then I would die from those complications. So, without being too graphic, I would actually be waiting to become septic. I have seen that happen and I know it is slow and I know it is painful.¹⁰⁸

It is not often that courts are confronted with a subject who can speak their fears about the precise nature of their own death scene. Ms B. feared the pain, distress and bodily disintegration that phased withdrawal entailed. Her concerns echo the observations made by Street and Kissane that 'the shame we feel at our own unboundedness, or that of another who is dependent on our care, needs to be constantly repressed' though, as they point out, this is never entirely possible.¹⁰⁹ Like the patients who requested euthanasia in Street and Kissane's study, Ms B. was unable to repress her 'horror of further disintegration and dependence'.¹¹⁰ Notably, B.'s fears were not only confined to the distressing physical aspects of dying, she was also concerned that the phased withdrawal would 'rob her' of 'a certain amount of dignity' and cause unnecessary distress to her loved ones.¹¹¹ In short, she was not just concerned that she be allowed to die, but to ensure that she was sedated so that she could expect it to be a quick and painless death. Significantly, the way in which her dying would be remembered and experienced by her family was a crucial consideration for Ms B. She wished to avoid a distressing and disconcerting death scene for her family and friends' sake as well as her own.

In *Rossiter*, the court addressed the issue of whether the medical regulation of death crossed the border into unlawful territory and simply declared that it did not. In *Ms B.'s* case, the court did not acknowledge the proximity of Ms B.'s request to assisted suicide. However, in endorsing Ms B.'s chosen dying trajectory over that of her doctors, it did, in effect, enable her to exercise some control over the manner in

which she would die. This raises an interesting tension when one considers that control over the dying trajectory is not available to those who are not dependent on life support but otherwise require medical assistance to die. These, too, are situations in which courts have heard dying subjects speak their fears about the nature of their death scene—individuals, for instance, with motor neuron disease, who wish to end their lives with dignity prior to the final gasping, distressing stages of their terminal illness.¹¹² Diane Pretty, a sufferer of motor neuron disease, challenged the prohibition on assisted suicide on the grounds that it violated her Convention rights. In effect, she asked for the same consideration as Ms B.: ‘I want to have a quick death without suffering, at home surrounded by my family, so that I can say good-bye to them.’¹¹³ Although the law regards the presence of life supporting technology as the crucial distinction between these cases, even this does not fully explain why Ms B.’s preferred dying trajectory was endorsed over her doctors’. The court respected Ms B.’s request for a quick death, but it did so without directly confronting the obvious inconsistency.

—CONCLUSION

Ms B. v An NHS Hospital Trust and *Brightwater Care Group (Inc.) v Rossiter* are not simply about the right to refuse treatment. They also engage the question of the extent to which an individual dependent on life support can claim control, not only over the question of whether they will live or die, but over the dying trajectory itself. This article has examined three legal fictions that were essential to law’s accommodation of Ms B.’s and Mr Rossiter’s requests to die. These fictions rest on particular legal characterisations of personhood, technology and death itself. Law characterises the individual’s decision as paramount when competent; life-sustaining technology as ‘artificial’ and therefore defeasible; and death following the treatment withdrawal as a natural death. However, as the foregoing analysis has shown, these characterisations do not adequately grasp the nuance and complexity of these death scenes. For instance, the individual’s choice may bear traces of ambivalence or ignorance; the omission to treat may be experienced as killing by others participating in the scene; and the ‘natural’ death may involve distressing efforts to cling to life that can only be ameliorated by careful orchestration of the dying process.

I have argued that these fictions are an expression of the law's underlying ambivalence about the choice to die. This ambivalence is especially evident where, despite the patient's clear choice to die, courts may need to be convinced that an individual deserves to have their choice respected; and where, despite the proximity of these death scenes to culpable ones, courts insist that there is a distinction.¹¹⁴ Although both courts took great care to avoid any unambivalent claim of the rightness of the choices made, there is nevertheless a sense that death for someone in the situation of Ms B. or Mr Rossiter is understandable. Each court's attempt to foreground the autonomy of these individuals, to understand the subjective character of their experience and the grotesqueness of a drawn out death are all testament to this ambivalent sensibility.

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—NOTES

The author would like to thank Laura Crommelin for her unfailing research assistance.

Abbreviations

AC	Appeal Cases
BMLR	Butterworths Medico-Legal Reports
Crim LR	Criminal Law Reports
DPP	Director of Public Prosecutions
EWCA	England and Wales Court of Appeal
EWHC	England and Wales High Court
HCA	High Court of Australia
NHS	National Health Service
NSWSC	New South Wales Supreme Court
QGAAT	Queensland Guardianship and Administration Tribunal
UKHL	United Kingdom House of Lords
WASC	Western Australian Supreme Court

¹ *Ms B v An NHS Hospital Trust* [2002] EWHC 429 (Fam).

² *Brightwater Care Group (Inc) v Rossiter* [2009] WASC 229.

³ There have been two earlier Australian decisions that have respected the competent decision to refuse treatment, though the first was in the context of a patient who was no longer conscious (*Hunter and New England Area Health Service v A* [2009] NSWSC 761) and the second was the decision of a Guardianship and Administrative Tribunal rather than a court (*Re PVM* [2000] QGAAT 1).

⁴ *Ms B v An NHS Hospital Trust* [2002] EWHC 429 at [5]–[6]; *Brightwater Care Group (Inc) v Rossiter* [2009] WASC 229 at [7].

⁵ *Brightwater Care Group (Inc) v Rossiter* [2009] WASC 229 at [11]; *Ms B v An NHS Hospital Trust* [2002] EWHC 429 at [39].

⁶ See for example: *Hunter and New England Area Health Service v A* [2009] NSWSC 761; *Secretary of Department of Health and Community Services v B (Marion's case)* [1992] HCA 15; *Re MB (Medical Treatment)* [1997] EWCA Civ 1361; *Airedale National Health Trust v Bland* [1993] AC 789; *Re T (Adult: Refusal of Treatment)* [1992] EWCA Civ 18.

⁷ Mercy killing is regarded by the law as murder even if motivated by compassion: *Airedale NHS Trust v Bland* [1993] AC 789, *R v Cox* (1992) BMLR 58, *R v Adams (Bodkin)* [1957] Crim LR 365 and all Australian jurisdictions, and the United Kingdom, prohibit assisted suicide: see, for example, *Crimes Act 1900* (NSW), s31C and *Suicide Act 1961* (UK), s2(1). A recent development in the UK has been the publication of DPP Guidelines on the exercise of prosecutorial discretion in relation to this offence, Policy for Prosecutors in respect of cases of encouraging or assisting suicide: <http://www.cps.gov.uk/publications/prosecution/assisted_suicide.html> (accessed on 5 March 2010). This follows the House of Lords decision in *R (on the application of Purdy) v DPP* [2009] UKHL 45.

⁸ For a recent review of the diversity of legal fictions and subterfuges, and some suggested reasons (including the masking of a normative choice) for their deployment, see P. Walsh, 'New Legal Fictions', *Georgetown Law Journal*, no. 95, 2007, p. 1435.

⁹ Although the legal person is an important legal category, and often described as a legal fiction, there is no agreement about its content and it is used in various senses: see 'Note: What We Talk About When We Talk About Persons: The Language of a Legal Fiction', *Harvard Law Review*, no. 114, 2001, p. 1746. Thus, in its most obvious 'fictitious' sense, the term may be used to denote a legal device to enable the operationalisation of law (for example, corporation as legal person). However, it is also used to denote when a human being can become a subject of law (for example, the born alive rule in criminal law) or a responsible subject (for example, an actor requiring a minimum level of cognitive capacity). See N. Naffine, 'Who are Law's Persons? From Cheshire Cats to Responsible Legal Subjects', *Modern Law Review*, no. 66, 2003, p. 346.

¹⁰ Naffine, 'Who are Law's Persons?', p. 362

¹¹ *Re T (Adult: Refusal of Treatment)* [1992] EWCA Civ 18.

¹² Ibid at [37]. This principle has been repeatedly endorsed by courts in England and Australia: see *Hunter and New England Area Health Service v A* [2009] NSWSC 761, *Secretary of Department of Health and Community Services v B (Marion's case)* [1992] HCA 15; *Re MB (Medical Treatment)* [1997] EWCA Civ 1361; *Airedale National Health Trust v Bland* [1993] AC 789.

¹³ As Butler-Sloss P. explained, 'It is important to underline that I am not asked directly to decide whether Ms B lives or dies but whether she, herself, is legally competent to make that decision': *Ms B v An NHS Hospital Trust* [2002] EWHC 429 at [12].

¹⁴ *Ms B v An NHS Hospital Trust* [2002] EWHC 429 at [95].

¹⁵ *Brightwater Care Group (Inc) v Rossiter* [2009] WASC 229 at [57].

¹⁶ *Brightwater Care Group (Inc) v Rossiter* [2009] WASC 229 at [24].

¹⁷ Ibid, citing Justice Cardozo in *Schloendorff v Society of New York Hospital* 211 NY 125 (1914), 129.

¹⁸ Naffine, 'Who are Law's Persons', p. 364.

¹⁹ Naffine, 'Who are Law's Persons', p. 364.

²⁰ Naffine, 'Who are Law's Persons', p. 364. See also N. Naffine and R. Owens, *Sexing the Subject of Law*, Law Book Company, Sydney, 1997; N. Naffine, *Law and the Sexes: Explorations in Feminist Jurisprudence*, Allen and Unwin, Sydney, 1990; K. Savell, 'The Mother of the Legal Person' in James and Palmer (eds), *Visible Women: Essays in Feminist Legal Theory and Philosophy*, Hart, Oxford, 2002, pp. 29–67.

²¹ A hospital record entry made at the time of her admission indicated that T. was an ex-Jehovah's witness and that she retained certain beliefs and practices. On three separate occasions prior to her lapse into unconsciousness, Miss T. indicated that she did not consent to have a blood transfusion. On one of these occasions she recorded her refusal in writing. *Re T (Adult: Refusal of Treatment)* [1992] EWCA Civ 18.

²² Ibid at [27]–[30] per Lord Donaldson MR, [44] per Butler Sloss J; [59] – [60] per Staughton LJ.

²³ Ibid at [31] – [32] per Lord Donaldson MR, [45] – [46] per Butler Sloss J; [57] per Staughton LJ.

²⁴ Ibid at [33] per Lord Donaldson MR, [51] per Butler Sloss J; [58] per Staughton LJ

²⁵ Ibid at [26] per Lord Donaldson MR.

²⁶ *Ms B v An NHS Hospital Trust* [2002] EWHC 429 (Fam) at [33] applying *Re C (Adult)(Refusal of Medical Treatment)* [1994] 1 WLR 290 at [295].

²⁷ D. Morgan and K. Vietch, 'Being Ms B: B, Autonomy and the Nature of Legal Regulation', *Sydney Law Review*, no. 5, 2004, p. 118.

²⁸ Morgan and Vietch, p. 118.

²⁹ *Ms B v An NHS Hospital Trust* [2002] EWHC 429 (Fam) at [42].

³⁰ Ibid at [40].

³¹ Ibid at [60].

³² Ibid at [63].

³³ Ibid at [35].

³⁴ Morgan and Vietch, pp. 121–2.

³⁵ *Ms B v An NHS Hospital Trust* [2002] EWHC 429 (Fam) at [53].

³⁶ *Ibid.*

³⁷ *Brightwater Care Group (Inc) v Rossiter* [2009] WASC 229 at [13].

³⁸ *Ibid* at [14].

³⁹ *Ibid.*

⁴⁰ *Ibid* at [40].

⁴¹ *Brightwater Care Group v Christian Rossiter* (No 2406 of 2009), Transcript of Proceedings, WA Supreme Court, 14 August 2009 at [23–4].

⁴² *Brightwater Care Group (Inc) v Rossiter* [2009] WASC 229 at [28]

⁴³ *Hunter and New England Area Health Service v A* [2009] NSWSC 761 [2009] NSWSC 761.

⁴⁴ *Brightwater Care Group (Inc) v Rossiter* [2009] WASC 229 at [29]

⁴⁵ *Ibid* at [49].

⁴⁶ One of the central challenges of the disability studies critique has been to shed light on the conceptualisation of disability as a necessarily negative characteristic, inherent to the individual. Overboe, for example, has argued that expressions of disabled life are negated as states of exception within a political economy that ‘favours a non-disabled orientation toward the social world’ (p. 220). Using Agamben’s terms, he claims to simultaneously embody political life (as an academic) and bare life (associated with his cerebral palsy) (p. 223): J. Overboe, ‘Disability and Genetics: Affirming the Bare Life (the State of Exception)’, *Canadian Review of Sociology and Anthropology*, no. 44, 2007, p. 219. This is an interesting observation, which seems to dovetail with the court’s constructions of Ms B. and Mr Rossiter as sovereign agents on the one hand and abject bodies on the other. However, as Street and Kissane, Waskul and van der Riet and indeed the cases under consideration show, ‘ableist’ thinking may be internalised by all, including severely disabled individuals. See A. Street and D. Kissane, ‘Discourses of the Body in Euthanasia: Symptomatic, Dependent, Shameful and Temporal’, *Nursing Inquiry*, vol. 8, no. 3, 2001 and D. Waskul and P. van der Riet, ‘The Abject Embodiment of Cancer Patients’ Dignity, Selfhood and the Grotesque Body’, *Symbolic Interaction*, vol. 25, no. 4, 2002.

⁴⁷ Waskul and van der Riet, p. 487.

⁴⁸ Waskul and van der Riet, p. 487.

⁴⁹ Waskul and van der Riet, p. 488.

⁵⁰ *Ms B v An NHS Hospital Trust* [2002] EWHC 429 (Fam) at [74].

⁵¹ *Ibid* at [61].

⁵² *Ibid* at [45].

⁵³ Street and Kissane, p. 162.

⁵⁴ *Ms B v An NHS Hospital Trust* [2002] EWHC 429 (Fam) at [63]

⁵⁵ *Ibid* at [92] – [94].

- ⁵⁶ *Brightwater Care Group v Christian Rossiter* (No 2406 of 2009), transcript of proceedings, WA Supreme Court, 14 August 2009, Martin CJ at [20–21].
- ⁵⁷ Waskul and van der Riet, pp. 498–99. See also Julia Kristeva, *Powers of Horror: An Essay on Abjection*, Columbia University Press, New York, 1982.
- ⁵⁸ Waskul and van der Riet, p. 499.
- ⁵⁹ Kristeva, p. 3.
- ⁶⁰ Kristeva, pp. 3–4.
- ⁶¹ Tom Koch, 'The Ideology of Normalcy: The Ethics of Difference', *Journal of Disability Studies*, no. 16, 2005, p. 123.
- ⁶² Fiona Campbell, *Contours of Ableism: The Production of Disability and Abledness*, Palgrave Macmillan, London, 2009, p. 5.
- ⁶³ *Airedale NHS Trust v Bland* [1993] AC 789 at [802].
- ⁶⁴ This part of the claim is dealt with in the judgment at [51]–[56] and will be dealt with in the next section.
- ⁶⁵ *Brightwater Care Group (Inc) v Rossiter* [2009] WASC 229 at [39].
- ⁶⁶ *Ibid* at [44].
- ⁶⁷ *Ibid* at [2].
- ⁶⁸ *Airedale NHS Trust v Bland* [1993] AC 789 at 823.
- ⁶⁹ *Ms B v An NHS Hospital Trust* [2002] EWHC 429 (Fam) at [12], [38], [80].
- ⁷⁰ P. Hopkins, 'Why Does Removing Machines Count as Passive Euthanasia?', *Hastings Center Report*, no. 27, 1997, p. 33.
- ⁷¹ Hopkins, p. 32.
- ⁷² Hopkins, pp. 30–1.
- ⁷³ Hopkins, p. 29.
- ⁷⁴ Hopkins, p. 35.
- ⁷⁵ Hopkins, p. 36.
- ⁷⁶ Hopkins.
- ⁷⁷ Hopkins, p. 37.
- ⁷⁸ *Ms B v An NHS Hospital Trust* [2002] EWHC 429 (Fam) at [47].
- ⁷⁹ *Ibid* at [74].
- ⁸⁰ *Ibid* at [48].
- ⁸¹ Robert Burt, 'The End of Autonomy', *Hastings Center Report (Special Report)*, no. 35, 2005, pp. s9, s10.
- ⁸² Burt, p. s11.
- ⁸³ Burt, p. s10.
- ⁸⁴ *Ms B v An NHS Hospital Trust* [2002] EWHC 429 (Fam) at [56].
- ⁸⁵ *Ibid* at [57].
- ⁸⁶ *Ibid* at [58].

- ⁸⁷ K. Mitchell, 'Physician Commitment in End of Life Care: Perspectives from New Zealand and the Netherlands', *Social Science and Medicine*, no. 59, 2004, p. 779.
- ⁸⁸ Mitchell, p. 779.
- ⁸⁹ Mitchell.
- ⁹⁰ M. Edwards and S. Tolle, 'Disconnecting a Ventilator at the Request of a Patient who knows he will then Die: The Doctor's Anguish', *Annals of Internal Medicine*, no. 117, 1992, p. 256.
- ⁹¹ Edwards and Tolle, p. 255.
- ⁹² Edwards and Tolle, p. 256.
- ⁹³ Edwards and Tolle.
- ⁹⁴ R. Pool, 'You're Not Going to Dehydrate Mom, Are You? Euthanasia, Versterving, and Good Death in the Netherlands', *Social Science and Medicine*, 58, 2004, p. 962.
- ⁹⁵ Pool, p. 963.
- ⁹⁶ Pool.
- ⁹⁷ J. Seymour, 'Revisiting Medicalisation and "Natural" Death', *Social Science and Medicine*, no. 49, 1999, p. 693.
- ⁹⁸ J. Harvey, 'The Technological Regulation of Death with Reference to the Technological Regulation of Birth', *Sociology*, no. 31, 1997, p. 724.
- ⁹⁹ Harvey, p. 726.
- ¹⁰⁰ Harvey, p. 726.
- ¹⁰¹ Harvey, p. 4.
- ¹⁰² *Ms B v An NHS Hospital Trust* [2002] EWHC 429 (Fam) at [98].
- ¹⁰³ *Ibid* at [98].
- ¹⁰⁴ J. Seymour, 'Revisiting Medicalisation and "Natural" Death', *Social Science and Medicine*, no. 49, 1999, p. 691.
- ¹⁰⁵ *Brightwater Care Group v Christian Rossiter* (No2406 of 2009), transcript of proceedings, WAS Supreme Court, 14 August 2009, Martin CJ at [25].
- ¹⁰⁶ *Ibid* at [32].
- ¹⁰⁷ *Brightwater Care Group (Inc) v Rossiter* [2009] WASC 229.
- ¹⁰⁸ *Ms B v An NHS Hospital Trust* [2002] EWHC 429 (Fam) at [46].
- ¹⁰⁹ A. Street and D. Kissane, 'Discourses of the Body in Euthanasia: Symptomatic, Dependent, Shameful and Temporal', *Nursing Inquiry*, vol. 8, no. 3, pp. 168–9.
- ¹¹⁰ Street and Kissane.
- ¹¹¹ *Ms B v An NHS Hospital Trust* [2002] EWHC 429 (Fam) at [45].
- ¹¹² Two examples from the United Kingdom are Diane Pretty (*Pretty v. Director of Public Prosecutions and Secretary of State for the Home Department* [2001] UKHL 61) and Debbie Purdy (*Purdy, R (on the application of Purdy) v DPP* [2009] UKHL 45). The ethics of ameliorating this stage of illness with the use of neuromuscular blockers and paralyzing agents has been the subject of discussion. See for

example: R. Perkin and D. Resnik, 'The Agony of Agonal Respiration: Is the Last Gasp Necessary?', *Journal of Medical Ethics*, no. 28, 2002, p. 164; H. Kuhse, 'Response to Perkin and Resnik: The Agony of Trying to Match Sanctity of Life and Patient-centred Care', *Journal of Medical Ethics*, no. 28, 2002, p. 270; L. Hawryluck, 'Neuromuscular Blockers: A Means of Palliation?', *Journal of Medical Ethics*, no. 28, 2002, p. 170. The limitation of this solution is that it seems to be intended to spare the feelings of others watching death rather than the dying patient.

¹¹³ Husband's tribute to Diane Pretty, *BBC News*, 13 May 2002,

<<http://news.bbc.co.uk/2/hi/health/1983941.stm>> (accessed 7 August 2010).

¹¹⁴ In practical terms, the distinction has been eroded further in the United Kingdom by the decision in *Purdy, R. (on the application of Purdy) v DPP* [2009] UKHL 45 to require the DPP to publish guidelines indicating when prosecuting the offence of assisted suicide is in (and is not in) the public interest (see note 7 above). This reliance on prosecutorial discretion (rather than legalisation) as a measure to ameliorate the harsh effects of prohibition stands as further testament to law's ambivalence about the choice to die.