

## What Is Good *for Them*? Best Interests and Severe Disorders of Consciousness

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Most people have very little knowledge of what neurologists refer to as “disorders of consciousness” and, consequently, little grasp of what it would mean to have such a disorder. Perhaps for that reason, insufficient attention has been given to questions about the best interests of such patients—about what would be *best for them*. This essay aims to rectify that omission. Attention to this question is all the more important in light of recent research that has called into question much of the previous understanding of what the lives of such patients may be like.

Of course, in the United States and in many other parts of the developed world, it is assumed that decision making for incompetent patients (who were previously competent) should, as much as possible, aim to reflect what the patient himself either wanted or would have wanted if he had thought it through. The preferred tools for decision making are advance directives and surrogates tasked with informing physicians what the patient would have wanted. In such a system, it is sometimes assumed that we do not need general philosophical reflection about best interests, because individuals make decisions for themselves, and caregivers simply follow these directions. However, this assumption is shortsighted. For even in this system, careful reflection about best interests has several important roles to play.

First, when individuals write advance directives, they try to understand what would really be in their own interests should various things happen to them. Later, at the bedside, caregivers may simply want to know what the patient wanted. But the patient, in formulating his directive is not asking himself what

he wants; rather, he is trying to understand what he *should* want. He wants to know what really would be in his best interests. Second, many individuals tell their loved ones—the ones who eventually become their surrogates—that if the need ever arises, the surrogate is to make the decision that he or she thinks would be *best* for the patient. Here again, although caregivers at the bedside may simply want the surrogate to do what the patient wanted, in many cases what the patient wanted was for the surrogate to make a judgment about best interests. Finally, there are always some cases where no advance directive exists and no one is very clear about what the patient wanted or would have wanted. In such cases, there is no alternative but to try to assess the patient's current best interests. For all of these reasons, we must reflect on these matters carefully. That way, when we as individuals are faced with such decisions, either for ourselves prospectively or for those who have entrusted themselves to our care, we will have something considered to guide us.

Most educated people are at least vaguely aware of one particular disorder of consciousness, the permanent vegetative state (PVS),<sup>1</sup> if only because of the media attention given in the past to cases such as those of Karen Ann Quinlan, Nancy Cruzan, and Terri Schiavo (Pence, 2008, Chapter 2). As popularly understood, PVS is the complete, permanent loss of all capacity for conscious awareness. Some patients end up in PVS as a result of losing oxygen to the brain for a prolonged period (as was true in the three cases mentioned), whereas others may enter PVS as a result of traumatic brain injury.<sup>2</sup> Unlike coma patients, PVS patients do have wake-sleep cycles as well as certain other reflexes and involuntary movements. But the general assumption until quite recently was that such patients lacked any degree of awareness.

The diagnosis of PVS depends on a prior diagnosis of vegetative state (VS). A diagnosis of VS, in turn, is made on the basis of what can be observed externally. It is diagnosed by the complete absence over time of even the most minute signs of voluntary movement or responsiveness (Multi-Society Task Force, 1994, p. 1500). When, over the further course of time, it becomes clear that a patient in VS is not going to improve, the diagnosis of PVS is given.<sup>3</sup> Some patients initially diagnosed as vegetative do subsequently improve. However, it is important to emphasize that very few of those who are in VS for longer than 1 year improve significantly. Still, it not infrequently happens that patients who once showed no visible signs of awareness later begin to show signs of *minimal* awareness.

To account for this, in 2002, the Aspen Neurobehavioral Conference Work Group introduced a new diagnostic category, that of the minimally conscious state or MCS (Giacino et al., 2002). Like VS it is diagnosed on the basis of what can be externally observed. It differs from VS in that some minimal, typically inconsistent, signs of awareness are detectable at the bedside. But it is part of

the diagnosis that communication with such patients via standard means is not possible.

Until recently, physicians felt confident making inferences about the interior life of such patients on the basis of these diagnoses. It was assumed that vegetative patients experienced nothing at all, and that minimally conscious patients experienced very little. But new research has raised interesting questions.

Using functional magnetic resonance imaging (fMRI) technology, researchers have demonstrated that some number of patients diagnosed as either VS or MCS have regular patterns of brain activation in response to verbal commands—patterns that closely resemble the patterns of brain activation observed in healthy volunteers (Monti et al., 2010). The researchers first developed two mental tasks—a motor imagery task that involved imagining oneself swinging a tennis racket and a spatial imagery task that involved imagining oneself walking through the rooms of one's home and seeing all the familiar items—which they knew would engage different, highly specific areas of the brain. Having once established what the fMRI brain scans of healthy people looked like when they performed these tasks, researchers scanned the brains of VS and MCS patients while asking them to perform the same two tasks. Most patients were entirely unresponsive (showing little or no brain activity).<sup>4</sup> But the shocking result was that a few (all of whom had suffered traumatic brain injury) seemed to be following the researchers' verbal commands: Their scans revealed patterns of activation very much like those of the healthy controls. These were individuals who in some cases had been VS or MCS for years.

Going a step further, researchers decided to try to communicate with a patient using these fMRI techniques. Having established with healthy controls the possibility of communicating in this way, they placed one VS patient in the scanner and told him he was going to be asked a series of questions. He was instructed to engage in mental task 1 if the answer to the question was "yes" and to engage in mental task 2 if the answer was "no." In a still more amazing result, the patient seemed to answer the questions correctly.<sup>5</sup>

It is hard to know precisely what these results mean, but it is clearly both fascinating (from the standpoint of science) and disturbing (for it is possible that these patients have been suffering for years unbeknownst to us). Interpreting these results is made more difficult by the fact that the involuntary, unconscious part of the mind is far more sophisticated, and controls far more of our behavior, than most of us realize. This raises the difficult question of whether what these researchers have observed is a function of involuntary, unconscious processes or whether, more excitingly, it is a function of the voluntary, conscious mind. It is hard to see how we could hope to answer that question with any certainty on the basis of current evidence.<sup>6</sup> But even if the best we can say is, "They might be conscious," this is important. For it radically changes our

understanding of these patients, undermining simple complacency about the nature of their experience. We can no longer be certain that they do not suffer, and this raises ethical questions about how we are to care for such patients.

My goals for this essay are twofold. First, I wish to articulate a general framework for thinking about the best interests of severely compromised incompetent patients such as patients in VS or MCS. In particular, I wish to articulate the two most important questions that ought to guide our thinking in this area, and to articulate as well some of the considerations that should go into answering these questions but all too often are overlooked or ignored. The two questions are simply these: “Do they suffer?” and “Are they deriving any benefit from their lives?”

My second goal is more substantive. I wish to defend an answer to the question of what would be best overall for patients in a PVS or a permanent MCS. I shall argue that, all things considered, it would be *better for them* to allow them to die. I limit my claims to these specific types of patients, because in these cases one does not have to struggle with the additional complicated question of how much weight to give to the possibility of future improvement. To grapple with that question would require some sense of how likely improvement is and also how great the improvement might be, factors that no doubt differ dramatically from case to case.

I also wish to acknowledge that my claim is based on assumptions about the feasibility of using certain types of technology in particular ways, and that if those assumptions are wrong or if they change, my conclusions might change as well. But the discussion to come will make it clear both what it would take for my conclusion to change and what it would change to. Moreover, although I am concerned about patients whose diagnosis is permanent, much of what I say is still relevant to thinking about the interests of patients who have not yet received that label. It is directly relevant to understanding their current interests, and it also helps us to frame what we need to ask about their future prospects. We would need some reason to hope that they might in the future improve to a point beyond minimal consciousness in order to conclude that their future interests provide us with reason now to continue their treatment.

I will assume throughout that we must view such patients as “incompetent” or as “lacking decision-making capacity.” I treat these terms as interchangeable, purely technical terms (Kim, 2009, chapter 1). They refer to a particular level of decision-making capacity that our society has decided individuals must possess in order to be granted a certain normative status—that of self decision-maker. Competent adults in our society have this normative status. They are presumed to be in charge of their own lives, such that a competent adult’s decision is the final authority when it comes to deciding what health care intervention he will receive.

Those who fall short of this standard must, of course, still be given excellent care and attention, but their currently expressed preferences (if they are able to express any) are not treated as authoritative. Final decision-making power lies in someone else's hands. It is worth emphasizing, because it is so frequently forgotten, that this does not mean that the person in charge of making decisions for an incompetent patient should neglect currently expressed preferences of the patient.<sup>7</sup> The person in charge of making a decision should consider and weigh everything that could possibly be relevant.

I nonetheless assume that the responses of VS and MCS patients in fMRI scans are not sufficient to license the conclusion that they are competent, leaving us to conclude by default that they are incompetent.<sup>8</sup> This matters, because some theorists have expressed the hope that we might be able to use fMRI technology and the yes/no communication task to ask these patients whether they are suffering or, even more dramatically, whether they wish to be kept alive in their current state (Monti et al., 2010, p. 589; Sinnott-Armstrong, 2011). But even if we eventually put such questions to these patients, and even if they respond, the mere ability to express a choice or preference is not generally considered sufficient to establish competency. In addition, a determination of competency usually requires showing that a person grasps the essential information, can relate that information to himself and his own situation (i.e., really grasp that it is relevant *to him*), and is not prone to obvious forms of logical error (Kim, 2009, Chapter 2). In short, we want to know a great deal about the quality of the processes—emotional and cognitive—that went into yielding the answer.

Moreover, it is extremely difficult to imagine how we could assess the quality of decision making for patients in VS or MCS. Yes/no answers are extremely limited in what they can reveal about a person's thought processes. This is not to deny that some day it may be possible to establish the capacity of some of these patients, but we are a long way from that now. Minimally, we would have to reach a point where we could communicate in a more open-ended way (i.e., moving past simple yes/no responses to questions) so that we could get a better sense of what the patient is thinking (if anything) independently of being prompted. For the time being, however, we must continue to view such patients as lacking decision-making capacity, and so we must continue to make decisions for them, in the same way as we do for other incompetent patients.

## THINKING ABOUT BEST INTERESTS

The question that interests me is a question about what is good *for* these patients. First, however, I want to make clear the relationship between different bits of

terminology used in different disciplines, remind readers of a few important distinctions, and delineate the guiding assumptions of my approach.

Bioethicists and lawyers tend to use the language of “best interests,” whereas philosophers refer to “welfare,” “well-being,” or, in the most general case, “prudential value.” The phrase “prudential value” is unfortunate in certain respects, for in ordinary language the word refers to adopting a self-protective attitude. Prudence in that sense requires adopting a general kind of cautiousness in one’s dealings with others; in some cases, more specifically, it requires great care in the handling of money. Yet in its philosophical usage none of these associations are intended. Prudential value is just the kind of the value that self-interest seeks to realize, and the kind of value that good lives contain lots of. It is concerned most broadly with all that is or can be good for an individual.

Despite its limitations, I prefer the phrase “prudential value” because of its neutrality. The terms “well-being” and “welfare,” in contrast, are explicitly concerned with the state of a person who is doing *well*, or for whom things are *good*. But human choices are concerned with more than just what is good absolutely (where this refers to being above some evaluative threshold). In cases where people are not doing well, we can still reasonably wonder which of the options open to them would be best overall. This is to wonder about which choice would be best from the standpoint of prudential value or, in other words, which choice would be good *relative* to the options available.

The relationship between good choices and prudential value can be complex for a number of reasons. To begin with, good choices must typically reflect an appropriate balance between concern for the present and concern for the future. A good prudential choice does not always maximize present value. Second, a choice can be good *intrinsically*, in that it directly increases prudential value in a person’s life, or *instrumentally*, by bringing a person closer to being able to realize something of prudential value. Finally, it is important to remember that although we often speak loosely of “doing what is good or best for someone,” this typically refers to making a good prudential *choice* for that person. In situations in which the option set is small and the possibilities grim, what counts as a good prudential choice may not be anything we would recognize as “good” without qualification.

How then is prudential value related to interests? As generally understood, interests are those things—events, persons, objects—that we have a stake in. A person is said to have an interest in something (e.g., an interest in obtaining or retaining a possession, an interest in having a certain relationship, an interest in the occurrence of a certain event) if that thing has the potential to affect the prudential value of his life. As this term is sometimes used in legal contexts, the potential to affect prudential value need only be slight, and in



such cases the terminology of interests can come to seem fairly remote from the terminology of welfare.

However, as I use the term, the intended link is tight. For example, in order for it to be true that a person has a positive interest in the occurrence of a particular event, it must be true either that the occurrence of this event would directly and immediately improve his life *or* that it would greatly increase the likelihood of improvement by moving him significantly closer to being able to realize some good. So, for example, a person has an interest in eliminating or decreasing his suffering, because this improves his life in a direct way. Similarly, it is in the interest of a young person who aspires to go to college to prepare well for the Scholastic Aptitude Test. Preparation is no guarantee of success, but it greatly increases the odds, moving the student significantly closer to the realization of something prudentially valuable for him. Talk of *best* interests is simply talk of what would be best overall for a person once all of his various interests have been considered. The notion of best interests is thus equivalent to the notion of what would, relative to the circumstances, be the best prudential choice for a person.

For the purposes of this paper, there is no need to offer a theory of prudential value, and that is fortunate, for such theories are often highly controversial. Interestingly, although there is often great disagreement about what makes a life positively good, there is considerably less disagreement about what makes a life bad. In this sense, there is an important asymmetry in ordinary thinking about best interests, and in this case that asymmetry works to my advantage. I shall restrict myself, then, to two claims about how we should approach the question of prudential value for severely compromised patients such as those with disorders of consciousness.

My first claim is that if anything can tip the balance in favor of death (i.e., if anything can make it true that it is in a person's overall best interests to die), it is extended suffering. Hence, we must always inquire as far as we can about the suffering of such patients. The basic idea that suffering is a form of prudential bad and that its presence makes a life worse is not very controversial. I shall assume, however, somewhat more controversially, that a life of extended suffering—a life *dominated* by suffering—is not worth living. I say more in the next section about the nature of suffering.

Second, in order for continued life to be in the best interests of a patient, I assume that he or she must be deriving some sort of benefit from continued life. From a certain perspective, this may seem obvious. But the typical focus in medical ethics on pain and suffering can often lead us to overlook this fact. The mere absence of suffering, while necessary, is not sufficient to underwrite the claim that continued life is best overall.

These, then, are the questions that should guide our thinking. I now wish to elaborate more fully on each question in turn and consider what these questions can tell us, if anything, about the best interests of patients who are permanently in VS or MCS.

## DO THEY SUFFER?

One of the more disturbing aspects of the recent fMRI-based findings is the worry that some patients previously thought to be entirely lacking in awareness might actually be suffering silently, internally, unable to reveal through any kind of voluntary movement what they are feeling and unable to receive any help. Discovering the existence and extent of suffering in these patients may be extremely difficult. Nonetheless, the question of suffering is clearly relevant in a way that means we must at least try to find out. Not only do we want to know whether they suffer, but, if they do, we want to know whether anything can be done to alleviate their suffering. And if their suffering cannot be alleviated, we need to remain open to the possibility that continued life may not be in their best interests.

But what exactly is suffering? What precisely are we trying to determine? Most people assume that the question before us is a question about pain. Clearly, pain is relevant, and if such patients experience pain, we should try to determine whether it can be medically treated.<sup>9</sup> However, I think the focus on pain is far too simple. Unlike many people, I draw a sharp distinction between pain on the one hand and suffering on the other.<sup>10</sup> In my view, “pain” picks out a certain class of physical sensations that occur in our bodies and which we find immediately and intrinsically aversive.<sup>11</sup> “Suffering,” however, is more complex. Suffering is *affective*. It has to do with the way we interpret our immediate physical experiences, as well the events of our lives and the events occurring around us. It is often, although not always, a reaction to pain. But pain can exist without suffering (think of the pain experienced by athletes in the course of training and performing), and suffering can exist without pain (think of the overwhelming grief of a parent who has just lost a child).

When I say that suffering has to do with interpretations and with meaning, I am not claiming that suffering is produced by conscious, deliberative thought processes. It is not. Indeed, in some cases, the interpretation of the world that informs an individual's suffering can coexist with, and be at odds with, that individual's more consciously held views. This occurs because the interpretations that yield suffering are the product of the *affective* side of our nature.

As psychologists use the term, “affect” is a general, all-purpose word for emotional phenomena. Emotions, as I understand them, are complex



dispositions to feel, think, and act in certain ways. Sadness, for example, disposes us to certain physical sensations, leads us to think certain thoughts, and creates a tendency toward certain kinds of actions. Moods are also dispositions, ones that shape our intuitive perceptions of the world in negative or positive ways. In addition to emotions and moods, we can view individuals as having broader, more general dispositions that determine the frequency with which they experience particular types of emotions, as well as good or bad moods. I shall call these *affective* dispositions. A person with a set of negative affective dispositions tends to experience more negative emotions and is implicitly disposed to see the world through a dark-colored lens. Suffering, as I understand it, is the product of extremely negative affective dispositions.

Pain and suffering, although distinct, are of course intimately related. For we human creatures are constituted in such a way that extended pain invariably leads to suffering. Pain in the body forces attention to itself in a way that diminishes the rest of mental life. In some cases, we attach a fearful meaning to pain (e.g., as a sign that one is sick or dying). But even when an individual understands that his pain poses no threat to his health (e.g., that pain is felt because a nerve has been damaged but otherwise one's body is intact and free of illness), it may still be that the pain, if extreme enough and prolonged enough, will lead him to suffer, for the simple reason that constant pain restricts in numerous ways a person's ability to derive value and positive meaning from other aspects of his life. It is because of the suffering pain can cause that we sometimes view a life of extreme pain as not worth living. But although pain often leads to suffering, the more important point for the purposes of this essay is that suffering can exist *even in the absence of pain*. An individual will almost certainly suffer, for example, if most of what he once cared for has been lost and he sees no hope for anything positive in his future.

When considering the question of best interests, courts have generally been open to the idea that a life of extended suffering may not be in the interests of an incompetent patient. However, they have typically understood suffering entirely in terms of pain. For example, in the famous case of Claire Conroy (*Matter of Conroy*, 1985), the Supreme Court of New Jersey articulated two best interest standards, both focused on pain, that it said could be used for making life-and-death decisions for incompetent patients in the limited case in which there was insufficient evidence of what the patient himself would have wanted. The first test, which the justices labeled the "limited objective test," required decision makers to be certain that the burdens of continued life with treatment (where burdens are understood in terms of pain that cannot be eliminated with treatment) outweigh any benefits the patient

is getting from his life, and also that there be some evidence that the patient would have wished to forego the treatment in such circumstances. According to the second test, the “pure objective test,” life-sustaining treatment may be stopped in the complete absence of evidence of a patient’s wishes if “the recurring, unavoidable, and severe pain of the patient’s life with the treatment would be such that the effect of administering life-sustaining treatment would be inhumane.”

In short, in the view of the majority in that case, it is only when a person is in pain, and the pain is as severe as that described, that we can be confident that it is in a person’s best interests to die. This strikes me as problematic in at least two ways. First, if one can be certain that the patient is not benefiting from his life (the topic of the next section), then there is no reason to insist that pain be so extreme. In such a case, the presence of chronic pain at any level should suffice to tip the balance. More importantly, however, there are forms of suffering that this account completely overlooks.

It may be that in the *Conroy* case, which involved a woman in the final stages of dementia, the justices whose views are reflected in the majority opinion assumed that the patient was not mentally intact enough to suffer, even if she could experience physical pain. Moreover, it is likely true that the possibility of suffering as I have described it increases as the level of internal mental capacity increases. Still, it seems that one of the lessons to be drawn from the recent fMRI studies is that we cannot always accurately predict interior life on the basis of exterior signs. If that is right, then we should be cautious about assuming that such patients do not suffer. We should instead admit that in most cases, we simply do not know.

When we consider the specific case of the five VS/MCS patients who were able to carry out simple mental tasks during fMRI, it is hard to know what to conclude. We do not know whether they are aware enough to think much, and we have no way of knowing what they can think about. Just because parts of the mind have been preserved, we still do not know whether these patients can remember much of their previous life, whether they experience emotions, whether they contemplate their current plight. But it does seem safe to assume that *if* these individuals are capable of thinking about and evaluating their current situation, they are most likely suffering in the extreme. For they have lost a great deal, have little or nothing to gain, and are isolated beyond imagining. Nor is it feasible, given the current costs, to suppose that fMRI will offer such patients a way to reconnect with their world. At best, right now, it may offer a few brief opportunities for limited exchange. Such a life is hard to imagine. However, because we do not know whether this is their life or not, let me turn for the moment to discussion of the second guiding question.

## DO THEY BENEFIT FROM LIFE?

Even in the absence of suffering, if we are to say that it is in a person's *best interests* to continue living, we must establish that life is *beneficial for him*. He must be deriving some benefit from his life.<sup>12</sup>

It can be easy to overlook the significance of this question, in part because theorists often frame the issue in terms of what it would take for it to be true that *death* is in someone's interest. But even if we grant that extended suffering makes death preferable to life, it does not simply follow that when such suffering is absent, life is thereby preferable to death. This way of thinking overlooks the fact that there are conditions an individual can be in where it is neither good for him to live nor good for him to die, where interests do not point one way or the other. The traditional understanding of PVS as the permanent loss of all capacity for awareness is a case in point, as is anencephaly in infants. When there is no capacity for awareness, continued life offers no opportunities for either benefit or harm.<sup>13</sup> One of the disturbing aspects of the recent fMRI findings is that we can no longer be sure which patients fall into this category. But we need to at least consider what would make continued life beneficial: What are the minimal capacities needed for being able to derive benefit from one's life?

In thinking about this issue I have found an older debate—a debate about when we ought to treat severely impaired newborns—illuminating. I do not mean that the issues are exactly parallel or that the two patient populations can be usefully compared, for they cannot. But I hope to put to use in a novel way some of the insights from this earlier discussion.

To understand this older debate, we need to remind ourselves of a dramatic shift in thinking that occurred in the 1960s and 1970s about how to make decisions for severely impaired newborns.<sup>14</sup> For centuries, majority opinion deemed handicapped lives to be not worth living. Although there are, no doubt, many factors that contributed to this opinion, it largely reflected the judgments of ordinary people that it would be terrible to become handicapped. In other words, people with species-typical physical and mental capacities tried to imagine what their life would be like were they to lose those capacities, and they concluded that it would not be worth much.<sup>15</sup> They did not, by and large, consider the nuanced question of whether limited capacities might still be better than none. Nor did they typically invest much effort in trying to imagine the perspective of someone who from birth had never possessed the full set of species-typical capacities. Because these prejudices were so dominant, the question of whether to attempt to save the life of a child born with disabilities usually turned on whether the parents were able and willing to care for the impaired child. Rather than actually wrestling with the difficult question of

whether a disabled child might, despite the handicap, have a reasonable chance at a decent life, people tended to let parental burdens settle the matter.

This attitude radically changed in the 1970s and early 1980s. When it did, new criteria for making treatment decisions for impaired newborns were needed. It was clear that some severely impaired children simply could not survive or could have only a short, miserable life. Hence, even though many agreed that the old system was bad, it was also clear to many of those involved that we should not simply try to save every child no matter what their condition.<sup>16</sup> Instead, it was suggested that we should be in the business of saving children whenever (as best we could tell) it was in a child's best interests to be saved.

As in other discussions of best interests, there was a general consensus that a life composed entirely of suffering could not be worthwhile.<sup>17</sup> But beyond that, consensus seemed to end. Some theorists maintained, and I would agree, that a child who is incapable of consciousness has no interest in continued life. For the anencephalic infant, as for an adult who has truly, permanently lost the capacity for consciousness, life is neither beneficial nor harmful. But what about those children who are born with severe cognitive defects but who have some small degree of consciousness?

The standard move at the time was to assume that as long as a child is sentient but not suffering, it is in the child's best interest to live. Some degree of awareness, however small, seemed to mark the boundary on the other side (i.e., the point at which life becomes a benefit). This view was defended, for example, by the legal theorist John Robertson in an influential essay from 1975 (Robertson, 1975, p. 269). Robertson thought that it was clearly in the best interests of many—and probably most—mentally handicapped children to live. But he recognized that there can be a real question about the interests of certain extremely impaired but nonetheless sentient children. He gave as his example the case of a “profoundly retarded, nonambulatory, blind, deaf infant who will spend his few years in the back-ward cribs of a state institution” (p. 254). We are to imagine that such a child's mental handicaps are severe enough that his conscious experience is at best highly fragmented. It is completely unclear what, if anything, he understands about his world.

Although recognizing such cases as the tough ones, Robertson ultimately concluded that it is in the best interest of such a child to live. However, his argument seems to boil down to the claim that it is in the child's best interest to live *because there is no harm for the child in such a life*. However, this confuses having a reason to live with lacking a reason to die. As mentioned earlier, it is possible to lack reasons of both sorts. It seems hard to imagine that a child as profoundly retarded and deprived of sensory input as the one he described could be deriving benefit from his life. Mere sentience is not in itself sufficient

for deriving benefit from life. Although Robertson is right that life is not a harm to the child, he has not shown that it is *good for him* to exist.

In an insightful essay from roughly the same time period, John Arras (1984) took issue with Robertson's conclusion. He clearly thought it a mistake to conclude that we should save children who are this severely impaired. But, unlike me, he was willing to simply cede the language of best interests to those who, like Robertson, claim it is in the best interests of such a child to live. In effect, he granted that it is in the child's interests to live, but argued that if that is so, we must move "beyond best interests" (p. 31). Although I agree with Arras' conclusion about the case, I think we should retain the language of best interests and say, instead, that it can be in the best interests of a child to live only if the child either has, or will in the course of normal development acquire, the capacity to derive benefit from living. This would still support the practical conclusion Arras favors—the conclusion that we should not treat such severely impaired infants. For I assume that when treatment is neither beneficial nor harmful to an individual, then it is perfectly legitimate to allow other factors to help determine the decision, even factors that would not normally be allowed to have weight.<sup>18</sup> In short, if a child cannot derive benefit from life, then it makes sense to consider the financial and emotional burdens of looking after the child and perhaps to decide that it is simply not worth it. Such a decision will not be detrimental to the child, because we have already stipulated that we are dealing with cases in which death is not a harm to the child.

Arras went on to consider under what conditions we should try to save impaired newborns. If mere sentience is not the important factor, what is? My suggestion is that we view this as a question about the minimal capacities necessary for life to be good for the individual whose life it is (or alternatively, the minimal capacities necessary for an individual to be able to extract value from his own life). In what follows, I want to consider two possible answers, the second of which is embraced by Arras.

The first answer is suggested by the way the question was framed. If life is valuable for a person only when he is capable of deriving value from it, then minimally it seems that the individual must be a *valuer*: a being capable of valuing. The notion of valuing has been understood in a number of different ways by different theorists. Philosophers, in particular, have tended to think of the mental capacity to value in highly intellectual terms, making of it a more complex capacity than what we need here. For example, some have suggested that in order to value something, one must view oneself as correct in valuing that thing.<sup>19</sup>

The notion of *caring* may be more helpful. Caring, as I shall understand it here, is a simpler capacity, one that we possess before we become valuers and one that we may sometimes retain even though we cease to be valuers. For

example, I assume that small children and many higher animals are capable of caring about things, even though they lack linguistic capacity and the more sophisticated cognitive commitments philosophers associate with valuing.<sup>20</sup> Minimally, to care about something, I must be capable of distinguishing it from other things in the world and (assuming the object of care is literally an object—something or someone in my environment)<sup>21</sup> capable of perceptually tracking it to some degree. I must also, of course, recognize the object of my concern over time. And this is not all. To care about X is to have certain, very primitive emotional dispositions vis-à-vis X. For example, I will be pleased or happy when I perceive X; I will want X to remain with me; I will be sad when X disappears; and so on. These simple capacities can be in place despite an individual's inability to articulate any of these feelings, and despite his having very little understanding of the person or thing he cares about.

I shall refer to this first answer as the answer *in terms of caring*. The idea is that when no suffering is present, a being with the capacity to care has at least some positive interest in living. An infant may lack this capacity at birth, but if he will develop it in the normal course of development, then it is in his best interest to live. However, beings permanently lacking this capacity are, like the anencephalic infant, neither benefited nor harmed by continued life, despite having some minimal degree of awareness.

The second answer was originally proposed by the Catholic theologian, Richard McCormick (1990),<sup>22</sup> and later taken up and endorsed by John Arras in the same essay discussed earlier (1984, pp. 32–33).<sup>23</sup> Call this the answer *in terms of relationship*. In this view, continued life is good only for those impaired infants who have (or will have in the course of normal development) the capacity for relationships with others.

A lot turns on what exactly we take a relationship to be. Just as it is possible to construe valuing in a way that makes it too complex for our purposes, it is similarly possible to describe the necessary requirements of genuine relationships in a way that is too complex. For our purposes, we should seek to describe the simplest possible form of relationship, and it is useful in this regard to consider the change that occurs in infants at about 3 months of age when, as people say, “social smiling” begins. Before that point, infants smile in random ways, almost as if they are just trying out their facial muscles. Of course, for all we know they might be smiling in response to pleasant feelings. There is no way to be sure. But even if that is so, it is not clear what significance this would have. For it is doubtful that such responses would be evidence of either the capacity to care or the capacity to engage in relationships.

Once an infant begins to smile socially, however, he begins to develop very simple relationships with other human beings—usually his mother and father. He grasps in the simplest sense that other people are distinct from him; he



recognizes and tracks particular people perceptually; and he responds to them in distinctive ways. The most minimal form of communication can begin to occur at this point, because the infant can share very simple feelings with the other person and learn in a very crude way about the feelings of others. This is not to say that he has any comprehension of what the feelings of others really are or mean. It is just to note the very simple fact that he smiles for their benefit (to see how they will respond) and looks for smiles in return. He grasps in a very simple way that certain gestures and looks are intended for him. Although by no means the richest of human relationships, this is, I think, a relationship. And although a life with no more in it than this would indeed be impoverished by our standards, it nonetheless seems plausible that in the absence of misery or suffering from other causes, a person with at least this level of capacity could extract something good from his own existence in a way that someone lacking such capacities could not.

Both of these answers—the answer in terms of caring and the answer in terms of relationship—contain important insights. In the case of impaired newborns, the capacity to care may come closer to capturing what we really think must be in place before life is beneficial, but the capacity for relationship may be easier to translate into some sort of concrete standard. Moreover, it is plausible that in developing children, the two capacities typically arrive at a similar point in time and serve to reinforce one another during the course of future development. The answer in terms of caring may also shed some light on why we think the capacity for relationship is so important, because it is only through sustained interaction with our world that we find an outlet for our caring. The capacity to interact with our world is necessary both so that we can locate objects to care about and so that, once we care, we can follow the objects of our concern. In short, without the capacity to relate to the world, the capacity to care would, at best, offer us nothing, and might in the worst case be simply a deep source of frustration.

Of course, our primary concern here is with the best interests of patients who have disorders of consciousness. What should we say about *them*? First, I think we should conclude, much as Arras did in the case of impaired newborns, that more than mere sentience is necessary for life to be a benefit. Second, I think that the two answers canvassed in the discussion of newborns—the answer in terms of caring and the answer in terms of relationship—can help resolve the question of whether patients with disorders of consciousness are able to benefit from life. But the way in which they may help is not immediately obvious.

The problem we face with these patients is that we do not know how mentally intact they are, or what their interior mental life consists of. We are, instead, in the extremely frustrating position of knowing only that previous estimates of their mental life were, in a small number of cases, deeply mistaken. We

now know that some such patients have more mental life than we previously thought, but that is not really saying very much. Nor are we in any position to know whether these patients have the capacities I mentioned in the discussion of newborns. Because they were previously competent adults, we know that they *once* possessed the capacity to care and the capacity for relationships. But we have no way of knowing to what extent those capacities remain intact and functional.

Nonetheless, despite our ignorance, there is one significant piece of information we possess that is relevant here. Whether or not these patients have the capacity to care, current resource limitations ensure that they cannot in their present state interact with their world or sustain meaningful relationships with others. The research suggests that they have the capacity to hear, but mere passive reception of sensory input, without the ability to respond to it, is neither sufficient for relationships nor an obvious benefit in its own right; it may instead simply be a source of deep frustration. Indeed, reflection on the case of patients with disorders of consciousness suggests that the capacity for relationship should really be thought of as a *set* of capacities. Some of these can be considered as “internal” mental capacities, such as the capacity to focus one’s thoughts on another person or object. For all we know, these kinds of capacities *may* be intact in these patients. But the capacity for relationship also requires the ability to communicate, if only in the most primitive ways. And, outside of the brain scanner, these patients show only intermittent signs of awareness and have no ability to communicate.

Nor do the fascinating results of fMRI technology suggest that this situation will change, at least not soon. It is not now, and is unlikely to be at any time in the near future, feasible for these patients to sustain relationships with others via fMRI. I shall return later to the issue of what it would mean if that were to change—if it were to become possible to sustain relationships with such patients via technology. But for now, because relationships are not possible, it seems clear that such patients are incredibly isolated. Given just how isolated they are, if they are mentally intact, it seems likely that they suffer and suffer greatly.

Therefore, it seems that despite our ignorance of the interior life of these patients, we can conclude that one of two things is true of their current state. On the one hand, it *may* be that the mental life these patients experience is so broken, fragmented, and confused that they lack the capacity to focus on, or care about, much at all. If that is the case, my view suggests that currently they are not deriving any benefit from life. If that is their permanent lot, then they never will derive benefit. In such cases, continued life is neither in the patient’s interest nor against it. On the other hand, it is also *possible* that such patients may be more intact mentally than even the results so far have suggested. But

even if that is the case, they are still extremely isolated. In these patients, too, because they cannot interact with their world or sustain even the simplest relationships with others, it is also likely that they do not benefit from life. But here, unlike the case of impaired newborns, we should not conclude that continued life is neutral, neither good nor bad. For *if* in this case the lack of capacity for relationship is partial—if it involves the lack of any ability to communicate coupled with fairly sophisticated interior awareness—then it is likely that such patients suffer.

Some will no doubt take issue with my inference from isolation to suffering and argue that we cannot *know* that these patients suffer (or that they would suffer if intact enough to be aware of much). Although I will certainly grant that we can't know for certain, I do think it is the most plausible view, and the kinds of considerations sometimes thought to cast doubt on this notion do not really do so. First, it is sometimes said that ordinary people vastly underestimate the quality of life of those who are severely disabled and that, to the surprise of those who are “normal,” many such individuals wish to remain alive.<sup>24</sup> That such mistakes are easy and frequent, I fully grant. Indeed, I usually find myself on the side of those who argue for a more fine-grained appreciation of the experience of those who are disabled, and I favor maintaining the life of most disabled people, even many of those who are severely cognitively disabled.<sup>25</sup> However, most disabilities, even extreme ones, do not leave individuals so isolated. Communication of some sort is typically possible, and such individuals can thus derive benefit from the love and care of others.

Second, it is sometimes pointed out that even patients with locked-in syndrome (LIS), a neurological disorder in which a patient is fully conscious despite being almost entirely unable to move, often desire to live (Doble, Haig, Anderson, & Katz, 2003; Laureys, Pellas, & Van Eeckhout, 2005).<sup>26</sup> Surely, this suggests that we should not be too quick to judge in the case of the minimally conscious. However, as I see it, this claim underscores just how poor we really are at seeing the differences and similarities that *matter* from the standpoint of quality of life. From our point of view, it may make sense to compare a patient with LIS with one who is minimally conscious, because both are completely bed-bound and completely dependent on high-level care, and because in both cases it is hard for us to know what is going on “inside.” But there is a difference here that makes all the difference. Most individuals with LIS are able to communicate, even if communication is laborious and burdensome.<sup>27</sup> Locked-In patients can thus maintain relationships with those around them. But when there is no way to interact with one's world and no way to communicate with people, I think that emotional suffering will almost certainly be present. And it is not likely that we can

eliminate such suffering, because we cannot (at least now) really address its root causes.

To summarize, if we focus simply on what we know about the current interests of these patients, we can reasonably assume that either life is neutral (neither beneficial nor harmful because the patient's consciousness is too fragmented), or it is negative (because the patient suffers). Thus, despite our inability presently to tell which is the case, we should conclude that it would be better overall to allow such patients to die. Assuming that things will remain as they are, death is either a neutral event or a great blessing.

However, this brings us back to the question of whether this state of affairs really is permanent. Even assuming that we restrict our attention to those patients for whom the *diagnosis* is permanent (i.e., they are permanently in VS or permanently in MCS as currently defined), there remains a question about whether relationships might one day be established with such patients via fMRI or some simpler technology. Indeed, one very interesting study has shown that electroencephalography (EEG) can be used to detect limited awareness in VS patients, in much the same way that fMRI has been used (Cruse et al., 2011). To date, this method has been employed only to test for patients' ability to follow simple commands (e.g., "Imagine you are squeezing your right hand into a fist and then relaxing it") and not for communication purposes. But perhaps it will eventually provide a way to communicate. Because EEG is so much less expensive, it is at least more feasible to think that this method might become widespread. If that came about, then I would, other things being equal, favor seeing whether it is possible to sustain meaningful relationships with such patients, relationships that would make their lives worth living and eliminate their suffering. However, much remains to be seen.

Two further cautions are in order. First, we should be careful not to fall into the trap of assuming that if communication is possible, sustaining life must be overall good for the patient. In my view, the possibility of relating to the world is a necessary condition of being able to derive benefit from life, but it is not a sufficient condition. Minimally, suffering must be absent as well. Although it seems plausible to assume that a completely isolated life would be a life of suffering (if the patient were mentally intact enough), there is no guarantee that suffering would disappear once some kind of interaction is established. This would depend on many factors. We can, for example, imagine a case in which even though we are able to communicate with a patient in a primitive way, the gap between what the patient is capable of thinking and what he can actually express might be intolerably large from his point of view. So, he might *still* suffer. Also, it may matter greatly how frequently the patient is able to communicate with others and whether he is able to communicate regularly with the particular people he wants to communicate with. It will presumably

also matter how temperamentally able the patient is to find new focuses in life and adapt to his position. People differ greatly in this ability. *If* we ever reach this stage, the answers to such questions will no doubt vary from individual to individual. So, even though life without relationships is not worth living, we must not assume that once relationships are possible, continued life is a pure benefit.

Second, and perhaps even more importantly, I am concerned about the conclusions some people may draw about best interests, given that right now such communication is not possible for the majority of patients in PVS or permanent MCS. I am worried that loved ones or courts may, with the best of intentions, seek to sustain the lives of such patients indefinitely in the hope of one day being able to re-establish communication. There is a common tendency to assume that future benefits or goods can justify almost any amount of current suffering or pain. But that is simply not true to lived human experience. A certain limited amount of suffering may be worth enduring if it is the only way to get to a future point at which great goods await us. But the goods in the future must truly outweigh the current negatives, and in many cases of extreme suffering, it is highly unlikely that the future can really redeem the present. I am thus not convinced that it would make sense for a family to decide today to continue treatment in a loved one because they hope that in the next few years fMRI or EEG may be available. Unless that family is in the position of knowing they will be able to try such a project within the very near future, within at most a few months, I think they risk leaving their loved one in a state that may be horrible—and doing so for no clear future benefit, or for a benefit that, while real, cannot justify the suffering that came before. We should thus exercise great caution in our judgments about these cases.

This last point is extremely important, because some theorists seem to have concluded (in light of the recent research findings) that things are looking up for PVS and MCS patients. But really, the picture has simply become much more complicated in a way that is deeply worrisome. Either such patients are beyond prudential value (in which case not much has changed, because that is what we used to assume), or they are capable of being benefited or harmed and may actually be suffering quite a bit. Although I will not deny that there are cases where it may make sense to try to establish some sort of connection with patients via technology, we should proceed very cautiously and hesitate to do anything that might prolong suffering. We should always keep in mind that despite our epistemic limitations, we know that currently things are either neutral for them or bad. So, the default assumption—which we could override, but which we should not override without carefully worked-out justifications—should be that it is best for these patients to allow them to die.

## CONCLUSION

I have argued that when we think about best interests, we need to consider not only the question of whether a patient suffers but also the question of whether he is getting anything positive out of his life. I assume that a life of extended suffering is not worth living, and that when the answer to the first question is a clear yes, we ought to allow the incompetent patient to die. Moreover, I think it is important to remember that suffering can be present even when pain is not (although we shouldn't forget about pain). Emotional suffering can do just as much to undermine the value of life as suffering caused by physical pain. Unfortunately, in the cases that interest us here, it is extremely difficult to know whether the patients suffer.

I have also argued that we should ask whether a person is deriving any benefit from his life. If he is, this must be considered and weighed against any burdens. There will be a category of patients for whom life is neither beneficial nor harmful. This is true, for example, of patients who have permanently lost all consciousness (although, as the recent research reveals, with certain classes of patients it is no longer so easy to determine when that has occurred). Nonetheless, when there is no conscious awareness, life is neither beneficial nor harmful. But the same also holds for some conscious patients, namely those who are cognitively incapable of caring about anything or of forming and maintaining even the simplest sorts of relationships.

Finally, I have argued that in the case of patients in PVS and permanent MCS, we may be able to get around some of the difficulties that arise from the fact that we have so little knowledge of what goes on inside. For even though it is not clear what precise level of awareness such patients have, it is likely that one of two things is true currently: Either they are in a mental position such that life is neither a benefit nor a burden, or they are more cognitively intact and thus able to be benefited, but because of their extreme isolation and inability to interact with anything or anyone they care about, their life is a life of suffering. They may have the internal capacities for forming and maintaining relationships, but they have no way to operationalize these capacities. In that case, life becomes a burden. Thus, if we limit ourselves to reflection on the current situation of such patients, best interests point toward allowing them to die. Death is either neutral or a blessing.

This conclusion must be qualified, of course, because it is based on claims about the importance of relationships and because it is at least possible that some of these patients may, at some point in the future, be able to maintain relationships. However, we must be extremely cautious here. Many issues unrelated to my topic of best interests (e.g., social policy questions about cost and access) will have to be solved before it even becomes possible to



try establishing relationships with such patients via technological means. Moreover, we should be very cautious about assuming that the improvement of being able to communicate will make life seem worth living for such patients. That will depend on many, highly individual variables. Nor should we rush to conclude that we ought to maintain such patients indefinitely until such time as it becomes possible to try communicating with them. Not all suffering can be compensated by future gains, and we must take seriously their current situation.

## NOTES

1. The abbreviation “PVS” can be used for either *persistent* vegetative state (a vegetative state that lasts longer than 1 month) or *permanent* vegetative state (an irreversible vegetative state, which is usually diagnosed after 1 year in a persistent vegetative state). For a description of the difference, see Multi-Society Task Force (1994, p. 1501). Because it is the *permanent* vegetative state that interests me most, I will use PVS to stand for that.
2. Some patients also end up in vegetative states in the final phases of degenerative or metabolic neurologic diseases, and some are vegetative as a result of developmental malformations of the nervous system (e.g., anencephalic infants). For a detailed list of the causes of vegetative states, see Multi-Society Task Force (1994, p. 1503).
3. A persistent vegetative state is labeled “permanent” when “the chance that the patient will regain consciousness is exceedingly small” (Multi-Society Task Force, 1994, 1501). The Task Force suggested that, for brain-injured patients, this point is at 1 year. Others, however, have disagreed, drawing a different conclusion from the same sample of 434 patients studied by the Task Force. Of 65 patients still alive and vegetative at 1 year, 7 patients (10.6%) went on to regain some degree of consciousness *after 1 year*. These authors contend that it is hardly fair to say the state is “permanent” at 1 year when 10.6% still go on to improve (see Borthwick, 1996; Stone, 2007). Despite this dispute, I assume there is *some point* at which we can conclude with high certainty that further recovery is extremely unlikely, even if the 1-year mark is not it. And I will assume for the purposes of this essay that “permanent” refers to patients who have passed that point, whatever it may turn out to be.
4. The study included fifty-four patients, thirty-one with a diagnosis of MCS and twenty-three with a diagnosis of VS. Patients varied considerably in the original cause of their disordered consciousness. Of the total, five patients responded to the motor imagery task, and four of them also responded to the spatial imagery task. Thus, out of the original fifty-four patients, roughly 9% responded. However, it is significant that all of the responders had suffered traumatic brain injury. There were thirty-three traumatic brain injury patients in the study, making the response rate *within that group* roughly 15%. This is important to keep in mind because, as of now, there is no reason to rethink our original understanding of the state of those patients who are vegetative or minimally conscious as a result of loss of oxygen, degenerative illness, malformation, or other nontraumatic causes. The findings appear to be applicable only to traumatic brain injury.

5. The patient who was given a “communication” scan had originally been diagnosed as VS, but after the study, he was rediagnosed on the basis of bedside observations as MCS (Monti et al., 2010, p. 583).
6. As other selections in this volume attest, I am not alone in being unclear about precisely what these results mean. Over the past 30 years, research psychologists have documented the astounding number of ways in which the fast-working part of the mind—what Daniel Kahneman (2011) has called our “System 1”—can process information and develop sophisticated responses without our even being aware of its operation. “System 2” is the label reserved for the conscious, voluntary part of the mind, which often adopts the suggestions of System 1. The variety and complexity of examples leaves me wondering whether with fMRI we are listening to a patient’s System 1 or System 2.
7. For just one of many possible examples, see Steffen and Franklin (1985, p. 13). They write: “Is Mr. B. competent to give or withhold consent to treatment? This is the central question, for if it is answered ‘no’ then the answer to the first question—how vigorously the staff should question him—is ‘not at all.’ It would be pointless to push Mr. B. for answers only to discard them as the views of an incompetent person.” The assumption is that the views of an incompetent person are irrelevant to treatment decisions, which in my view is too strong.
8. In ordinary cases, adults are presumed to be competent until they show signs of incompetency, at which point an assessment must be conducted. However, because these patients have suffered severe brain injuries and have been unable to communicate until now, the presumption is reversed, and we can and must assume that they are incompetent until we have sufficient evidence of competency. On the presumption of competency, see Buchanan and Brock (1990, Chapter 1).
9. On the topic of pain, see also Valerie Gray Hardcastle’s entry in this volume, “Minimally Conscious States and Pain: A Different Approach to Patient Ethics.” She and I agree that it is highly relevant whether or not a patient is in pain, and we agree that much more should be done to try to treat pain in such patients. Hardcastle has her own distinctive reason for thinking that we ought to treat all VS and MCS patients for pain, although I am not sure I am convinced by it. However, the question is overdetermined, because there are already sufficient reasons for thinking that we ought to be doing more to treat pain in VS and MCS patients.
10. Eric Cassell, whose work has greatly influenced my own, makes a similar distinction between pain and suffering. Like me, Cassell (1982, 1991) sees suffering as being about *meaning*. However, my own, more detailed account of suffering differs from his.
11. Observant readers will note that this definition of pain requires pain to be conscious, signaling a difference between Hardcastle’s use of the term “pain” (Chapter 12 in this volume) and my use of it. She uses the word “pain” to refer to specific brain processes that underlie certain aversive experiences, whereas I use it to refer to those experiences directly. Her view allows her to say that pain is present whenever these processes are occurring, even if the subject is not conscious. I would simply say that pain processes can occur whether or not the person feels pain. Either way, an interesting question arises, which we would each state

slightly differently. She would ask, “Does pain matter when it is not felt?” I would ask, “Do pain processes matter when they do not produce felt pain?” Hardcastle says “yes” for reasons having to do with the brain damage caused over time by untreated chronic pain. Although I would agree with her for most patient populations, I remain unconvinced for the special case of patients in PVS or MCS.

12. A nice example of an instance in which theorists do insist that we ask this question is found in Dresser and Robertson (1989, p. 240).
13. (Warning: This is a footnote for philosophers. Everyone else can feel free to ignore it.) Some philosophical readers may object that this assumes the truth of some sort of mental-state theory of prudential value as opposed to a state-of-the-world theory (Griffin, 1986, p. 17). Among philosophers, at any rate, such theories are highly controversial, so if it were true, that would indeed be problematic. However, no such assumption is being made. The standard example of a state-of-the-world theory is the desire theory, according to which what is good for someone is getting what he wants, here understood as *the coming true of his desires*. Because desires can come true without our knowing it, the theory implies that we can be benefited (or harmed) without our knowledge. What people sometimes fail to see, however, is that even with a state-of-the-world theory like the desire theory, it is unlikely that life would benefit a permanently unconscious patient or that such a patient could be said to have an interest in continued living. A permanently unconscious patient forms no new desires, and his old desires fall into one of two categories: Either they have already been frustrated or satisfied (e.g., the desire of a patient to some day swim the English Channel, was frustrated on the day he entered PVS), or they remain open, in the sense that future events in the world may either satisfy or frustrate those desires—but this can happen equally well whether the patient lives or dies. (For example, suppose a patient, while competent, had worked hard to raise awareness of the importance of literacy and founded a program to improve literacy in the schools of her city. She hoped that one day the schools would embrace her program and incorporate its fundamental principles into the basic curriculum. At the time of her injury, this desire had not yet been satisfied. If it were to happen while she is in PVS, desire theorists would say that this is good for her; it adds value to her life, even though she is unaware of it. But they would say *the exact same thing* if it happened after she died.) In short, state-of-the-world theorists think that a permanently unconscious person retains a number of interests, and they object to the common assumption that beings lacking the capacity for consciousness have no interests. But my claim is not that such beings lack interests; rather, but they lack *an interest in continued life*. And in the vast majority of cases this will be true precisely because the interests that remain do not typically depend in any way on whether the patient lives or dies.
14. For a detailed historical overview, including brief descriptions of many significant cases, see Pence (2008, Chapter 8).
15. Psychologists know that individuals are not, generally, good judges about such matters. For example, healthy individuals typically assume that they would be much less happy living with a particular disability than, in fact, most people are who actually do live with that disability. Although there remain complex debates about how best to understand the existing data, it seems safe to

say this much: Individuals with even severe disabilities frequently value their lives greatly, and typically much more than nondisabled persons suspect. (See Albrecht & Devlieger, 1999; Brickman & Janoff-Bulman, 1978; Damschroder, Zikmund-Fisher, & Ubel, 2008.)

16. There were, of course, exceptions. The Reagan Administration's policies famously rejected any quality-of-life judgments and insisted on saving every child. Moreover, in a few cases, the administration's "Baby Doe squads" demanded extraordinarily invasive treatment that, in the end, gave an infant only a few extra days of life (see Pence, 2008, p. 202).
17. My discussion of newborns may strike some readers as overly simplistic because I am focused on only one aspect of decision making. It is important when thinking about newborns to distinguish between questions about what capacities a child must have if he is to derive benefit from his life and, on the other hand, *epistemic* questions about when we can be certain that those capacities exist or will be likely to exist. Given how extremely difficult it is for physicians to predict what a newborn child will be capable of later on, epistemic considerations will often lead us to err on the side of treatment, particularly if the child is not suffering. I think that both questions (about capacities and about our ability to detect them) are important, but in the context of this chapter, in which it is the question of capacity that has relevance for my larger topic, ~~so~~ I focus on that.
18. A similar point was made by Dresser and Robertson (1989, p. 240).
19. For example, Agnieszka Jaworska (1999, p. 114) stated that part of what it is to value something is to think that it would be a loss to oneself if one were to stop valuing it. And in a later paper on caring, she explicitly argued that valuing (but not caring) requires seeing oneself as *correct* in one's attitudes (Jaworska, 2007, p. 541).
20. Jaworska, like me, uses the word "caring" to denote something simpler than valuing, an attitude that can be had by individuals who lack some of the more sophisticated cognitive requirements necessary for valuing. However, two points are in order. First, although Jaworska uses "caring" in a simpler sense, not all philosophers follow this example. Some construe caring in ways that make it almost as complex as valuing (see, for example, Frankfurt, 1989). Second, even Jaworska uses it in a way that makes it more complex than I wish it to be understood here. I allow that young infants and many higher animals *care*, whereas Jaworska (2007, p. 564) is explicit that, on her account, infants and animals do not care, but 2-year olds and patients in the middle stages of dementia do care. Ultimately, I may need to find a third term to put to use for my own purposes, but for the moment, it is sufficient that the reader understand caring in terms of my actual description of it here.
21. Caring itself does not literally require these kinds of perceptual and tracking capacities, but they would be necessary for one to begin to care about an object or a person in one's environment. And infants would need such capacities to get started as carers. However, more cognitively sophisticated beings might care about ideas or other abstract things, and for that, perceptual capacities and tracking capacities would not be necessary.

22. McCormick saw the relationship standard as deriving from Christian theology. He argued that life is a relative good given to us by God for the pursuit of certain spiritual ends, namely, the love of God and neighbor. He argued that it is through our love of *others* that we encounter and come to love God. Hence, “the meaning, substance, and consummation of life are found in human relationships and the qualities of justice, respect, concern, compassion, and support that surround them” (McCormick, 1990, p. 30). Because he envisions relationships as a way to grow morally and engage with the divine, it has always seemed to me that he must have a rather sophisticated notion of relationship, one that would demand more in the way of capacities than my own account would. So although I find his initial idea appealing, I am willing to adopt it only in a severely altered form. Moreover, I do not think it needs religious underpinnings, for it is independently plausible to think that the capacity to engage in relationships is a minimal requirement for being able to derive benefit from life.
23. How Arras intends to understand the nature of relationships, however, is not fully clear.
24. For example, this argument was used by Jim Stone (2007, p. 89) to support the idea that we should maintain patients who are minimally conscious. However, the kinds of “disabled” individuals discussed by Stone to make his case are in a very different category from those who are minimally conscious. Although they are cognitively disabled (he described his own sister, a stroke victim, who could not “read, write her name, or count past three”), they are able to communicate, relate to others, and derive enjoyment from their lives. I am thus not persuaded that their case is at all relevant to those involving disorders of consciousness.
25. Again, my view implies that we need a way of distinguishing within the class of severely cognitively disabled patients those who have the capacity to care or to maintain simple relationships and those who do not. Those who have such capacities clearly benefit from life, whereas those who lack even these simple capacities neither benefit from nor are harmed by continued life.
26. Despite such reports, there remains some controversy about what the life of a locked-in patient amounts to, with many arguing that such a life must be one of unbearable suffering. Indeed, because many people think such lives must be awful, locked-in patients are sometimes allowed to choose death relatively soon after their diagnosis—which would not happen, for example, with many other severe disabilities, where it would be assumed that patients need time to adjust. (See, for example, Kompanje, de Beaufort, & Bakker, 2007.) I allow that for those rare patients who are *completely* locked-in (i.e., cannot communicate even via eye signals), continued life may simply be a continuation of suffering. But this is based on the same reasoning as my claim that minimally conscious patients, who are nonetheless somewhat cognitively intact, almost certainly suffer. In both cases, relationships are impossible. This is also true for those patients who have not been recognized by others as being locked in, but at least here there is hope for improvement. Were someone to recognize their state, communication could be established. The locked-in patient Julia Tavalaro wrote a memoir describing (among other things) her frustration and misery during the 6 years it took for others to realize she was locked-in (Tavalaro & Tayson, 1997). All of this is compatible

with the thought that in most cases being locked-in need not lead to unbearable suffering, because in most cases communication remains possible and, therefore, so do relationships.

27. The most common methods make use of the fact that the patient can blink or move the eye up and down. Using a yes/no system and alphabet listings, patients can select one letter at a time, thus creating their own communications that are not dependent on the questions of others (see Laureys et al., 2005, pp. 501–503, 505–506).

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