

# ENDING THE LIFE OF A N·E·W·B·O·R·N

## The Groningen Protocol

by HILDE LINDEMANN AND MARIAN VERKERK

Several criticisms of the Groningen Protocol rest on misunderstandings about how it works or which babies it concerns. Some other objections—about quality-of-life judgments and parents' role in making decisions about their children—cannot be easily cleared away, but at least in the context of Dutch culture and medicine, the protocol is acceptable.

Since its publication in 2005,<sup>1</sup> the Groningen Protocol has been under fire both in the Netherlands and outside it. The purpose of the protocol is to set a standard of practice for doctors to responsibly end the lives of severely impaired newborns, but it also lays out procedures for reporting doctors' decisions to authorities. Doctors who end the life of a baby must report the death to the local medical examiner, who in turn reports it to both the district attorney and to a recently created review committee. (The procedure differs in this respect from the black-letter law governing voluntary euthanasia. There, the medical examiner sends the report only to the regional review committee, which alerts the district attorney only if it judges that the physician acted improperly.) The protocol was creat-

ed by a committee of physicians and others at the University Medical Center Groningen in consultation with the Groningen district attorney and has been ratified by the National Association of Pediatricians, but it does not give physicians unassailable legal protection. Case law has so far protected physicians from prosecution as long as they act in accordance with the protocol, but no black-letter law exists in this area.

The protocol stands accused of various crimes: (1) it is aimed primarily at babies with spina bifida, many of whom could lead satisfactory lives;<sup>2</sup> (2) it fails to distinguish with clinical precision between babies whose prognosis of death is certain and those who could continue to live;<sup>3</sup> (3) it allows parents to commit infanticide as a means of escaping an unwanted burden of care;<sup>4</sup> (4) it lets doctors decide what is an acceptable quality of life;<sup>5</sup> (5) it lets doctors determine the morality of their own actions;<sup>6</sup> (6) it provides a purely procedural response to the problem of measuring subjective suffering;<sup>7</sup> (7) it con-

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done infanticide rather than preventing spina bifida or promoting its early detection via fetal ultrasound, followed by abortion;<sup>8</sup> and (8) it offers an incoherent criterion for deciding whether to end an infant's life—it requires that the infant experience “hopeless and unbearable suffering,” but neonates cannot suffer because they lack the ability to realize intentions, desires, and hopes for the future.<sup>9</sup>

Many of these claims rest on a serious misunderstanding and, together, they give a highly distorted picture of the protocol. In this paper we attempt to clear up these misunderstandings by several acts of translation: we render into English the Dutch words in which the protocol was written, but at the same time we try to convey to an English-speaking readership the relevant aspects of the Dutch cultural and social background that make those words intelligible. And then, because we want to make *ethically* intelligible the practice that the protocol is intended to guide, we engage in a further act of translation—first we explain the shared moral understandings that form the context in which Dutch physicians sometimes end the lives of severely impaired newborns, and then we identify the issues for which understandings have not, or have not yet, become shared. Through these translations we argue for the moral permissibility, in the Dutch context, of physician intervention to bring about the death of babies who fall within the category the protocol is meant to address.

### What the Protocol Says

Eduard Verhagen and Pieter Sauer, the two pediatricians at the University Medical Center Groningen most intimately involved in developing and publicizing the protocol, have identified three categories of newborns for whom doctors must make end-of-life decisions.

Group 1 consists of newborns with no chance of survival. Typically, they have a fatal disease such as severe lung or kidney hypoplasia, and they are put on life support immediately after birth while their physicians determine the extent of the damage. While “in some cases they can be kept alive for a short period of time, . . . when the futility of the treatment is apparent, the ventilatory support is removed so that the child can die in the arms of the mother or father.”<sup>10</sup> The decision to withhold or withdraw treatment in this group is, as Verhagen and Sauer correctly note, acceptable for physicians in Europe as well as in the United States. Indeed, once it is clear that the newborn has no chance for survival, to continue or

it is better for them to die. No quality-of-life judgments are involved.

Group 2 consists of infants who “may survive after a period of intensive treatment, but expectations regarding their future condition are very grim.”<sup>11</sup> They include infants with severe brain abnormalities or extensive organ damage caused by lack of oxygen. The dilemma here is whether these infants are so badly off that they should be allowed to die. In the Netherlands and in most parts of Europe, doctors agree that not only survival but also the quality of the life is important in deciding whether to withhold or withdraw treatment. In the United Kingdom, the Nuffield Council on Bioethics recently wrote, “It would not be in the baby's best in-

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**CRITICS** charge that the protocol does not successfully identify which babies will die. But it is precisely those babies who could continue to live, but whose lives would be wretched in the extreme, who stand in most need of the interventions for which the protocol offers guidance.

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even to start treatment would be medically irresponsible.

However, if the baby does not die immediately after life support is removed, the doctors could face a severe moral conflict. On the one hand, they are morally and legally bound to relieve suffering; on the other, they are bound to preserve and protect the infant's life. In the United States, doctors in the throes of this dilemma may not intervene to hasten the baby's death. In the Netherlands, however, the deliberate ending of a life is countenanced as morally and legally justified. Because infants belonging to group 1 cannot live very long no matter what treatment they receive, the decision about terminating their lives is only a decision about the time of dying, not about whether

interests to insist on the imposition or continuance of treatment to prolong the life of the baby when doing so imposes an intolerable burden on him or her.<sup>12</sup> In the United States, too, there is a consensus regarding the permissibility of withholding or withdrawing life support for babies in this category.

In the Netherlands, however, if neither withholding nor withdrawing intensive treatment will result in a speedy death, the unbearable suffering of the infant is seen as a compelling reason for the doctor to end its life directly. In the United States this would count as an appalling breach of medical ethics, as it also would in the United Kingdom: the Nuffield Council makes very clear that “the active ending of neonatal life

even when that life is ‘intolerable’ is rejected.”<sup>13</sup> But in the Netherlands, the termination of these infants’ lives has not caused much controversy. The decision for deliberately ending the life of a group 2 baby involves not only a question of when death should take place, as is the case for babies in group 1, but also a value judgment about the infant’s quality of life: the baby is judged to be better off dead than forced to endure the only kind of life it can ever have.

While the termination of life for group 2 babies would cause an uproar in the United States, from the Dutch point of view the controversial group is group 3. This group comprises babies with an extremely poor prognosis “who do not depend on technology for physiologic stability and whose suffering is severe, sustained, and cannot be alleviated.”<sup>14</sup> These are infants who are not and have not been dependent on intensive medical treatment and who, with proper care, can in some cases survive many years, even into adulthood. They have serious conditions that cannot be treated but cause terrible suffering, such as epidermolysis bullosa, which in severe cases produces large, painful, fluid-filled blisters and continual scarring that fuses the fingers and toes and leads to feeding and swallowing difficulties. Other severe conditions include progressive paralysis, complete lifelong dependency, and permanent inability to communicate in any way.

The Groningen Protocol is applicable to all three groups, but because there is a consensus in the Netherlands regarding the moral permissibility of ending the lives of babies in groups 1 and 2, critics have particularly attacked the protocol’s application to babies in group 3. The protocol consists of two sections—one setting out the conditions necessary for euthanasia to be performed, and the other detailing the kinds of records that should be kept “to clarify the decision and facilitate assessment.”<sup>15</sup> We translate it in its entirety (see sidebar).

### How the Protocol Was Developed

To understand the protocol, one must set it against the backdrop of the wider Dutch practice of euthanasia and assisted suicide. In the Netherlands, euthanasia is usually understood to mean ending the life of another person at their express request. Assisted suicide is taken to mean providing another person with the means to commit suicide. Under Article 294 of the Dutch Criminal Code, suicide is not a criminal offense, but assisted suicide is. Euthanasia is likewise a criminal offense under Article 293 of the Code.

However, since the Termination of Life on Request and Assisted Suicide Act went into effect on April 1, 2002, both of these articles have included special grounds for immunity from criminal liability. This means that termination of life or assisted suicide are not offenses if performed by doctors who comply with the “due care” criteria of the act and report their actions to the medical examiner. The medical examiner performs an external examination to ascertain how the patient died and what substances were used to terminate life. He or she then sends all the necessary documents and any others that may be relevant to one of the five regional review committees—each made up of at least one legal specialist, one physician, and one expert on ethical or philosophical issues—whose duty it is to assess them. On the basis of the documents, the committee decides whether the physician acted in accordance with the due care criteria.

About 1,950 cases of euthanasia are reported to the review committees every year, and while committees occasionally request additional information from a physician, cases are generally approved without further action. Most of the physicians who perform euthanasia are *huisartsen* (literally, “house doctors”)—family-care physicians who pay house calls and typically have an established and ongoing relationship with their patients. Most

of the patients who receive euthanasia are end-stage cancer patients.

The due care criteria, aimed at insuring that euthanasia is correctly performed, are these: 1) a voluntary and well-considered patient request; 2) the presence of unbearable suffering without prospect of improvement; 3) informed consent; 4) no reasonable alternative; 5) consultation with at least one other independent physician; and 6) a medically appropriate termination of life.

As might have been expected, much of the language in the protocol’s “Requirements” section was drawn directly from the euthanasia due care criteria. Provision 1 (that the request is voluntary) could not be incorporated into the protocol, as babies are incapable of voluntary requests. But provisions 2, 5, and 6—hopeless and unbearable suffering, consultation by an independent physician, and terminating life in a medically appropriate manner—were taken over nearly verbatim by the Groningen committee. Provision 3 (that the patient be informed) was imported into the Groningen requirement that both parents give informed consent. Provision 4 (no reasonable alternative) does not appear in the protocol’s requirements, but under “Information needed to support and clarify the decision about euthanasia,” alternative treatments are to be described and presumably judged unacceptable.

Where the authors erred, we believe, is in carrying the language of “euthanasia” into the protocol. That word causes confusion because in the Netherlands it is reserved for terminating the life of a mentally competent patient at the patient’s considered request. Babies are not mentally competent, so they can neither judge for themselves that their lives are unbearable nor request that they be helped to die. In the case of infants, then, rather than speak of euthanasia, we think it is better to use the language of “ending life.”

The Groningen committee also relied on legal precedents to develop

the protocol. In 1996, the courts acquitted doctors in two cases, one involving a newborn with an extreme form of spina bifida, and the other an infant with severe trisomy 13. In both cases, despite palliative care, the babies suffered extensively and the doctors ended their lives with lethal drugs. “The courts accepted,” wrote Verhagen and Sauer, “that the physicians had to choose between the duty to retain life (and accept the severe suffering) and the duty to limit the suffering (and end the life of the child). They considered the choice to end the life of the infants justified because there was no alternative.”<sup>16</sup>

There is, of course, an alternative; what Verhagen and Sauer meant to say is that the alternative is worse than death. What is important here, however, is that in both cases the decision to deliberately end life was made only after it had been decided that all other medical treatments should be withdrawn. Neither baby fell into the category of group 3.

Finally, the Groningen committee considered twenty-two instances of life-ending interventions that were reported to district attorneys’ offices between 1997 and 2004, all involving “infants with very severe forms of spina bifida.”<sup>17</sup> Again, in all these precedents, the decision to end life was preceded by a decision to withhold further life-sustaining treatment. The prosecutor assessed each case by means of four criteria: whether the babies had endured hopeless and unbearable suffering and a very poor quality of life, whether the parents had consented, whether an independent physician had been consulted, and whether the physician had ended the infants’ lives in accordance with proper medical standards. None of the physicians were prosecuted.

### How the Protocol Is Misunderstood

While some of the criticisms that have been leveled against the protocol are based on genuine moral disagreements, others seem to rest on

## The Groningen Protocol for Euthanasia in Newborns

### Requirements that must be fulfilled

- The diagnosis and prognosis must be certain
- Hopeless and unbearable suffering must be present
- The diagnosis, prognosis, and unbearable suffering must be confirmed by at least one independent doctor
- Both parents must give informed consent
- The procedure must be performed in accordance with the accepted medical standard

### Information needed to support and clarify the decision about euthanasia

#### *Diagnosis and prognosis*

- Describe all relevant medical data and the results of diagnostic investigations used to establish the diagnosis
- List all the participants in the decision-making process, all opinions expressed, and the final consensus
- Describe how the prognosis regarding long-term health was assessed
- Describe how the degree of suffering and life expectancy were assessed
- Describe the availability of alternative treatments, alternative means of alleviating suffering, or both
- Describe treatments and the results of treatment preceding the decision about euthanasia

#### *Euthanasia decision*

- Describe who initiated the discussion about possible euthanasia and at what moment
- List the considerations that prompted the decision
- List all the participants in the decision-making process, all opinions expressed, and the final consensus
- Describe the way in which the parents were informed and their opinions

#### *Consultation*

- Describe the physician or physicians who gave a second opinion (name and qualifications)
- List the results of the examinations and the recommendations made by the consulting physician or physicians

#### *Implementation*

- Describe the actual euthanasia procedure (time, place, participants, and administration of drugs)
- Describe the reasons for the chosen method of euthanasia

#### *Steps taken after death*

- Describe the findings of the coroner
- Describe how the euthanasia was reported to the prosecuting authority
- Describe how the parents are being supported and counseled
- Describe planned follow-up, including case review, postmortem examination, and genetic counseling

misinterpretations, mistranslations, or other misreadings. Criticisms of this kind can be readily deflected.

We begin with the confusion that seems to have arisen over the class of babies to whom the protocol is applicable. In this regard, the criticism that the protocol fails to distinguish with clinical precision between babies whose prognosis of death is certain and those who could continue to live misses its mark.<sup>18</sup> It is precisely those babies who could continue to live but whose lives would be wretched in the extreme who stand in most need of the interventions for which the protocol offers guidance. The whole point of the protocol is to help physicians end the lives of newborns who are so severely afflicted that neither their dying nor their living should be prolonged. That being the case, the pertinent distinction is not between babies who will die and those who could live, but between babies for whom life-ending decisions should be made and those for whom such decisions cannot be morally justified. In bringing within its compass babies who are in no danger of dying—and, indeed, with proper care could live to adulthood—the protocol is even more radical than its critics supposed.

Another misunderstanding regarding the relevant class of babies is that the protocol is aimed at babies with spina bifida. In fact, nowhere in the protocol is spina bifida represented as a condition associated with an utterly unacceptable quality of life.<sup>19</sup> In our view, Verhagen and Sauer are partly responsible for the confusion that has arisen over this point, because by invoking the twenty-two reported cases of physician aid-in-dying used to develop the protocol, all of which involved infants with spina bifida, they unintentionally created the impression that spina bifida per se is paradigmatic of babies for whom end-of-life decisions are made. It isn't. As dissenters quickly pointed out, many people with spina bifida enjoy their lives, and while "the variable spectrum of disabling conditions associated with spina bifida may cause bur-

dens on parents and society at large," society has an obligation to shoulder that burden.<sup>20</sup> We agree, and we have no reason to doubt that the Groningen committee shares our view. To put it as plainly as possible, the protocol is not intended for disabled babies with even modest prospects for lives free of intense suffering. The mere presence of a disability is no more relevant to an end-of-life decision than is a sprained ankle.

We take seriously the social stigma that attaches to people with disability and the disgraceful history of medical mistreatment that is a particularly vicious manifestation of that stigma. As we see it, however, the Groningen Protocol guards *against* the abuse of people with disabilities because it sets out clear requirements for the condition—dire in the extreme—that a baby must be in before ending its life is permitted.

A further point can be made here. The supposedly morally superior alternative to the actions governed by the protocol, of promoting the detection of spina bifida in utero and aborting affected fetuses,<sup>21</sup> does not strike us as superior at all. Because there is a very broad range in the degree to which spina bifida disables people or requires painful treatment, and because a great many people who have the condition live perfectly satisfactory lives, we join disability activists who condemn the routine recommendation of abortions performed for no other reason than to prevent the birth of an affected baby.

A third criticism rests on a confusion over how the protocol operates. It is not, nor could it be, purely procedural.<sup>22</sup> The protocol is intended to make the decision-making process more transparent, but this does not at all mean that the decisions themselves can be arrived at by ticking off a procedural checklist. Determining whether a baby's suffering is intolerable, whether a diagnosis and prognosis are reliable, whether or to what degree a treatment might be efficacious, whether a mother and father are fully appraised of their baby's condition

and what it means—all this requires a sophisticated knowledge of medicine, a good deal of experience, and above all, judgment. While the protocol serves to guide physicians' deliberations on these matters by itemizing what needs to be thought about and what needs to be done, it also performs what is perhaps an even more useful function: it allows doctors to be openly accountable for their decisions to all members of society.

The importance of this accountability cannot be overestimated because unlike malpractice-minded Americans, Dutch people by and large trust their doctors. The Netherlands is not a particularly litigious society, nor are its physicians as troubled by the pressures of big pharma, entrepreneurial conflicts of interest, and inequities in the health care delivery system that have eroded the doctor-patient relationship in the United States. But the trust between the Dutch people and their physicians does not exist merely in the absence of reasons for distrust; it is deliberately cultivated as a socially valuable good. Much about Dutch medical practice—house calls, adequate funding for mental health care, the fact that 30 percent of babies are delivered at home—helps maintain the confidence the Dutch public reposes in its doctors. The transparency of the process of reflection and action required by the Groningen Protocol serves as another mechanism for nurturing and strengthening this trust.

### Lingering Problems with the Protocol

While criticisms based on misreadings of the protocol are easily cleared up, other concerns still remain. These have largely to do with quality-of-life judgments and with the role of the parents.

*Quality-of-life judgments.* The protocol requires that "hopeless and unbearable suffering" be present. But hopelessness worries some critics of the protocol because it seems far too subjective for ending the life of an-

other human being.<sup>23</sup> My reason for losing hope might be your reason to press on; what plunges me into hopelessness may stiffen your spine.

We believe that the brunt of this criticism can be deflected by considering the Dutch word from which the English one was translated. That word is *uitzichtloos*, which literally means “outlook-less,” or, in better English, “without prospect.” While not all are hopeful who have reason to hope, and some continue to hope when all hope is gone, agreement can be reached concerning a baby’s prospects for improvement. Parents and physicians alike may hope the baby will get better while agreeing that there is no prospect of it. It’s true that the determination that there is no prospect is a judgment, not a self-evident fact, but it is a judgment that will have been based on clinical data and medical expertise, and it will have been confirmed by a second, independent opinion.

The harder quality-of-life judgment to establish is that of *unbearable suffering*.<sup>24</sup> How can I know what you cannot bear unless you tell me, and if you’re a newborn baby, how can you tell me? *Unbearable*, like *hopeless*, strikes some critics as an unacceptably subjective criterion. Nor does *suffering* fare any better. It has become a bioethical commonplace to distinguish suffering, which is subjective, from pain, which is not. Pain, it is said, is “the awareness of reports of tissue damage or threat of tissue damage in the central nervous system.”<sup>25</sup> It is a sensation caused by physiological phenomena. Suffering can be distinguished from pain, according to Eric Cassell’s well-known formulation, as “the state of severe distress associated with events that threaten the intactness of the person.”<sup>26</sup> It is awareness of the disintegration, or the danger of disintegration, of one’s sense of self.

If one accepts this distinction, the difficulty with the protocol becomes obvious: infants, whose psychologies are not yet complex enough to produce a sense of self and who do not

experience themselves as intact persons, are incapable of suffering. As the objection has it, criteria based on suffering, if they are to be used at all, must be reserved for euthanasia because criteria of this kind could only be applicable to people with self-concepts and the ability to report what they feel.<sup>27</sup>

While Cassell’s distinction can be most helpful in some contexts, we see no particular reason to follow it here. There is a perfectly ordinary sense in both English and Dutch in which one can suffer pain—just as one can suffer humiliation, cold, fools gladly, or the consequences. Babies, being babies,

baby alive until it begins to experience intolerable suffering.

It also raises two sorts of difficulties. The first has to do with whether physicians ought to be in the business of mounting lethal preemptive strikes before any actual suffering has occurred. In September 2006, the Ministry of Health Care empanelled the review committee we mentioned earlier—a group of experts (a lawyer, an ethicist, and several physicians) charged with retrospectively assessing cases in which physicians have ended the lives of severely impaired newborns. Once the committee has spoken, it sends its judgment to the dis-

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are severely limited in the range of things they can suffer, but they can certainly suffer pain, and to excruciating degrees. These degrees are observable and measurable and do not require a self-concept or self-reporting to be accurately assessed. In the absence of untenable assumptions about the impossibility of knowing what is in another person’s mind, the objection about the subjectivity of the language of unbearable suffering does not seem persuasive, at least with regard to pain.

The trouble, though, is that the protocol has been taken to apply not only to pain, but also to other kinds of serious and unrelievable conditions—total lifelong dependency, for example, or lack of any capacity for communication, or progressive paralysis resulting in total immobility. The protocol thus leaves room for cases in which the suffering will take place in the future. This forward-looking feature of the protocol is justified on the grounds that it is inhumane to keep a

district attorney, who has already received a report of the death. The district attorney, on the basis of the review committee’s recommendation, then decides whether to act on the case. Thus, the review committee here acts solely in an advisory capacity. It differs in that respect from the regional euthanasia committees, which, because they report cases of improperly administered euthanasia to the district attorney, serve in a prosecutorial capacity. But while the review committee for ending the lives of infants does not wield the same power as the euthanasia review committees, it will, if it thinks that the physician has acted improperly, send its judgment to the Inspector of Health Care—the government agency whose U.S. analog is the Joint Commission on Accreditation of Healthcare Organizations and which, like that body, has the power to shut the hospital down. The committee uses roughly the same due care criteria as the euthanasia review committees, adding to those cri-

teria the particular requirements of the Groningen Protocol. However, it is not yet clear whether the intense, unrelievable suffering of the newborn must be actual, or whether intense, unrelievable suffering in the near future is also acceptable grounds for terminating the newborn's life.

It is possible that the committee will come down on the side of caution, ruling that only actual suffering provides an acceptable reason.<sup>28</sup> But that, we think, would be a pity. We can see no reason why, in at least some cases, the more responsible course of action might not be to end an infant's life in advance of intense, unrelievable suffering it will otherwise surely have to endure. For babies who either cannot be treated at all or who face a future of one surgery after another, none of which is likely to improve the quality of their lives to any marked degree, the prevention of later suffering that cannot be alleviated would seem to be just as morally valuable as the relief of present unbearable pain. It is of course true that some of these babies—those, for example, who face complete lifelong dependency—might, if kept alive, judge as adults that their lives had been worth something to them. Much would depend, one supposes, on how much pain and other kinds of suffering they had to endure to get to adulthood. But that consideration is no reason to proscribe all life-ending interventions on the basis of future suffering.

It is a matter of the greatest importance that more research be conducted to better determine what it is to live with conditions that cause serious suffering other than pain. In the absence of such research, physicians might succumb to the biases of the able-bodied, who tend to think disability is much worse than disabled people actually find it. That said, the fact remains that on rare occasions, a doctor can find herself in a situation in which she has good reason to believe that her obligation to prevent suffering outweighs her duty to protect her newborn patient's life.

The second concern raised by the protocol's stance that physicians may base end-of-life decisions on future suffering is the morally hazardous nature in general of making quality-of-life judgments for others. Aid in dying for patients who rationally request it can be justified by appealing to the moral concept of respect for autonomy. Such patients have weighed the quality of their current state against what they have to look forward to, and they decided for themselves that the game is no longer worth the candle. They are in the best position, both morally and epistemically, to intentionally lay down a burden that has become too heavy for them. Deciding for *others* that they have (or will have) an unacceptable quality of life is quite another matter. It seems the height of arrogance to conclude that someone else's life is not worth living, and even worse to deprive the person of all her experiences, possibilities, and relationships on the basis of that conclusion.

On the other hand, where there is a socially shared understanding that death is not the worst thing that can befall a human being, quality-of-life judgments cannot be evaded. Advances in medical treatment have meant that more and more deaths in developed nations must be negotiated. These negotiations often require family members, in consultation with health care professionals, to decide when an uncomprehending patient's life is no longer of value to him. In the United States, where fully one-fourth of all people die in intensive care units,<sup>29</sup> these decisions on behalf of others routinely result in withdrawing or withholding further life-sustaining treatment so that the patient may die. In the Netherlands, too, there is a shared understanding that families may need to pass judgment on a loved one's quality of life so that life-sustaining treatment can be refused or withdrawn.

Where the Dutch go further than other countries is in their shared belief that even newborns have a fundamental interest in not prolonging a life

that is or will become an intolerable burden to them. This understanding is buttressed by a consensus—within the National Association of Pediatricians, for example, but also in the wider community—on some criteria regarding quality of life, including the amount of suffering that is to be accepted, the capacities for communication (nonverbally as well as verbally), the capacities to live a self-supporting life, and the dependency on care institutions. It is one of the harsh realities of twenty-first-century medicine that quality-of-life judgments must be made. What we must not do is pretend that we do not already make them, and that there is somehow something morally different about doing it for a newborn baby.

One might object that even if we do make quality-of-life judgments for others, there is surely a moral difference between killing and letting die. In fact, sometimes there is, and sometimes there isn't. As James Rachels has famously argued, whether you drown your six-year-old nephew in the bathtub so that you can collect his inheritance or merely refuse to intervene as he slips and hits his head and falls face down into the bathwater, either way you are a murderer.<sup>30</sup> We agree with Rachels that actively ending a life can sometimes be more humane than waiting for the person to die, and that in the desperate cases where death does not come of its own accord to end unendurable suffering, the morally right thing to do is to summon it.

We realize that this is controversial. The recent report of the Nuffield Council argues that permitting doctors to end neonatal life deliberately would likely not only cause psychological harm to the doctors who do it, but also have a negative impact on how the medical profession is perceived more widely. Parents in particular might lose their trust in doctors.<sup>31</sup> Again, we think that this argument underestimates the difficulty doctors themselves experience when they come to their decisions. Every doctor will testify that the deliberate killing of a child is very hard. But in

these cases, a conflict of duties has been judged to exist, and the need to relieve the baby's severe suffering has outweighed the need to protect its life.

*The role of parents.* Another lingering concern has to do with the parents' role in these life-ending decisions. Because parents bear the responsibility of caring for their children and may find the care of severely impaired children burdensome in the extreme, the objection has been raised that the parents of such babies have a conflict of interest: they will be tempted to kill the baby so they don't have to look after it.<sup>32</sup>

Two points are worth making here. First, "parents" is generally a euphemism for "mothers." In the Netherlands as everywhere else, by far the greatest amount of responsibility for the care of infants is assigned to their mothers, regardless of whether the father is present in the household or the mother works full time outside the home. When infants are disabled, the mother is almost always the full-time caregiver.<sup>33</sup> Yet who is worried about conflict of interest? Of the five authors who to our knowledge have voiced this objection—Alan B. Jotkowitz, Shimon Glick, Frank A. Chervenak, Laurence B. McCullough, and Birgit Arabin—all but one are men. Because childcare (let alone familial care of badly damaged children) is socially devalued and heavily gendered, it is unseemly, to say no more, for those who are neither expected nor likely to do it to attribute malign intentions to those who must.

This is, of course, an ad hominem argument. But it is also an appeal to attend to the social context in which the objection is raised, and to the position of social immunity from maternal responsibility enjoyed by those who raise it. We take seriously the "epistemology of ignorance"<sup>34</sup> that allows some people not to have to notice social arrangements that are uncomfortable or awkward: often, what social privilege amounts to is not being forced to acknowledge things

that it would be inconvenient to bear in mind. And we suspect that this is what has happened here. The criticism that the protocol allows parents to wiggle out from under the responsibility to look after their disabled children strikes us as both unmotivated and mean-spirited: it does not take seriously either children with disabilities or the mothers who care for them.

The second point is that parental conflicts of interest arise routinely, yet responsibility for the care of the

Parents play a role in these life-ending decisions that no one else—not even the most caring physicians or dedicated nurses—can fill. They are ordinarily the initiators and major contributors to the long process of shaping their children's selves, enveloping their children with their own "thick" normative framework and in that way giving them some rich and comprehensive notion of what matters in life. Because they so directly mark the child in its first few years when children are at their most

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young continues to be assigned to their progenitors. Absent evidence to the contrary, parents are trusted not to abuse or neglect their offspring despite the many occasions on which it would be convenient or financially remunerative to put their own interests first. We do not assume that parents shouldn't be trusted with the care of their five-year-old simply because they could leave the child untended while they go out for a night on the town, nor do detectives follow a new mother home from the hospital to make sure she doesn't skimp on her baby's formula to avoid a dip in her disposable income. To create public policy on the assumption that parents are likely to sacrifice their desperately ill child's interests to their own would be to overturn deep-seated, widely shared understandings about who is responsible for the care of the young. Concern about conflict of interest in parents' making end-of-life decisions of any kind for their children needs to be specific and substantial, not general and notional.<sup>35</sup>

receptive, parents provide a window into the values and settled preferences, the particular outlook on life, that might well characterize the child when grown. It is a tiny window, smudged and dim, but it is the closest glimpse we have into the assessments their baby might itself make about the quality of its life.<sup>36</sup> When parents make decisions about the treatment of babies who are very badly damaged, then, they do not and should not decide on the basis of some impersonal and impartial best-interests standard. They do it out of an intermingling of selves that marks this particular baby as nested within the value structure of these particular parents, uniquely situated to judge what quality of life their child would find unacceptable.

At present, parents in the Netherlands may request that their severely impaired babies' lives be terminated, but their request does not automatically prevail. However, if the doctors believe that the child's life should be ended but the parents do not agree,

the parents' wishes are honored. One reason the parental role is limited to giving or withholding consent may be that things happen very quickly in a neonatal intensive care unit: a baby's condition can change drastically in a matter of hours, so that while the health care professionals remain abreast of the changes, parents often have a difficult time keeping up.<sup>37</sup> They are, therefore, not always in the best epistemic position to assess whether it is time for an end-of-life decision to be made. A second reason may be that because physicians are the ones who actually end the life of the baby, the decision to do so must be a joint one.

Nevertheless, we believe that because parents typically love all their children, regardless of the children's medical needs, and because they are especially well placed to make judgments about the acceptability of a given quality of life for their babies, it is important to include parents in the decision-making process. Moreover, it is important to take parents' interests, wishes, and fears very seriously. Too often in the United States, family members are told that they must not consider anything but the interests of the patient; to do otherwise is to court suspicion of neglect or abuse. Indeed, in both the United States and the United Kingdom, this refusal to countenance informal caregivers' concerns seems to be a permanent fixture of bioethics.<sup>38</sup> In the Netherlands, they arrange these matters differently. Because parents feel that they are equal partners in the decision-making process, they seem content to let the final decision rest with the physicians who are directly responsible for their babies' care.

As our defense of the protocol suggests, we think it is essentially sound, though no more foolproof than any set of guidelines can be. Determining in an instant case whether the protocol is applicable will always require judgment, and because the stakes are inordinately high no matter what is decided, the judgment must be made with fear and trembling. That said,

however, we believe that transparency in the deliberations concerning the ending of an infant's life—which is just as important as it is in the deliberations concerning euthanasia in adults—is adequately promoted by the protocol's requirements.

Concerning the larger question of whether the practice for which the protocol was developed can be morally justified, we think it can—in the Netherlands, at any rate. When a tragically impaired infant is born into a society that is hospitable to its children, offers universal access to decent health care, and promotes an ethos among its citizens whereby they look after each other as a matter of course, we believe that the doctor's ending the baby's life could be the best, most caring response.

As we wrote this paper together, it was brought home forcibly to each of us, at different times, just how deep the cultural and social divide is between the Netherlands and the United States. Although we are tolerably well acquainted with each others' countries and have worked together for a number of years, we found that we were continually making assumptions that the other didn't share, which resulted in a fair amount of talking past each other. For example, it took four extended conversations before we were satisfied that we had spelled out the differences between groups 1, 2, and 3 in a way that would be fully intelligible to an American audience. This experience served to strengthen our jointly held conviction that if bioethics is to do its proper work of carefully describing and assessing any particular biomedical practice, it must provide an empirically saturated (read: culturally nuanced) and socially situated analysis of that practice. Sometimes, as in the present instance, this requires translation—of cultures as well as concepts. And because concepts take on whatever meaning they do against a backdrop of what Wittgenstein called “forms of life,”<sup>39</sup> we wish to repeat that while we find it morally permissible for Dutch doctors to end the lives of severely im-

paired neonates according to the requirements of the Groningen Protocol, we are not prepared to suggest that American physicians should follow suit. The United States has its own forms of life, and not all of them support this way of caring for desperately ill infants when there's nothing else to be done.

### Acknowledgments

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