

EUTHANASIA OF NEWBORNS AND THE GRONINGEN PROTOCOL

Until now, only three countries in the world have decriminalised euthanasia: the Netherlands, Belgium and Luxembourg. This practice is available only to people who are mentally competent when they apply (if necessary, via a declaration in advance requesting euthanasia).

A notable exception to the voluntary nature of the request for euthanasia concerns newborns who face suffering that is deemed intolerable and who have no prospect of enjoying an acceptable “quality of life” at any point in the future. In a text written in 2004, entitled the Groningen Protocol, Professor Eduard Verhagen, Head of the Department of Paediatrics at the Medical Center of the University of Groningen in the Netherlands, provides criteria to enable doctors to deliberately end the life of severely ill newborns.

First we outline the content of the Groningen Protocol, specify its legal status in the Netherlands and present several statistics. Then we review the main criticisms of the Protocol. Finally, the issue of withholding futile medical care in the specific case of newborns is discussed.

The Protocol

Professor Verhagen’s point of departure, in his article published in 2005 in the *New England Journal of Medicine*¹ on the *Groningen Protocol*, is the following statistic: of the 200,000 babies born each year in the Netherlands, approximately 1,000 die before reaching their first birthday. Of these deaths, about 600 are the result of a so-called medical decision. In the great majority of cases, these decisions focus on the possibility (or not) of starting or continuing extensive treatment. It is widely accepted that it is better not to start or continue a treatment that is difficult for patients and which offers no real prospect of improvement in their condition. In these circumstances, it is not appropriate to delay unnecessarily the natural process leading to death. So most of these decisions arise from what the medical community labels “withholding futile medical care”.

However, in the eyes of the author of the *Protocol*, withholding futile medical care does not provide a satisfactory solution in all cases. Hence there is a need, from his point of view, to resort to euthanasia. Although decriminalised in the Netherlands for adults (and for minors of 12 years or more), it has

not been decriminalised for newborns, who are unable to express their wishes. So it is other people who decide whether the lives of the latter are worth living and, if not, put an end to them.

Three scenarios

To clarify the debate, Professor Verhagen considers three scenarios:

- 1- Newborns with **no chance** of survival. Think, for example, of patients with *hypoplasia* of the lungs or kidneys.
- 2- Newborns who require **intensive care to survive**, with a poor prognosis and very poor quality of life. These cases include, for example, infants with severe cerebral malformations or whose organs have been damaged as a result of extreme *hypoxemia*.
- 3- Infants for whom there is no hope in the long term and who, in the eyes of the parents and the medical team, are suffering unbearably. These are patients whose **survival does not depend on intensive care**, but who are expected

to have a **very poor quality of life and to suffer intensely**. In particular, these patients include infants suffering from a severe form of *spina bifida*, who will have a poor quality of life, even after numerous operations, and infants who have survived thanks to intensive care and whose outlook for quality of life is very poor, with no prospect of improvement whatsoever.

According to Professor Verhagen, terminating the treatments of newborns who have no prospect of survival (**scenario 1**) is a matter of withholding futile medical care. This approach is considered “good practice” in Europe and an “acceptable practice” in the United States.

The professor views **the second scenario** from a different perspective; in line with the thinking of Dutch neonatologists and the majority of European neonatologists, he argues that the goal of intensive care is not only the infant’s survival, but also the guarantee of an acceptable quality of life. It then follows, according to Professor Verhagen, that for the majority of neonatologists, forgoing intensive care is acceptable if the parents and the medical team are confident that they are acting in the best interest of the newborn, whose quality of life is predicted to be very poor. This viewpoint lies at the very limits of the concept of withholding futile medical care, or indeed beyond it, because the medical decision rests on the extremely problematic concept of “quality of life”.

In the **third scenario**, the author of the *Protocol* goes even further, by affirming that circumstances exist in which, despite the measures taken, suffering cannot be alleviated, and no improvement can be expected. The author continues: “[When both the parents and the physicians are convinced that there is an extremely poor prognosis, they may concur that death would be more humane than continued life.]” Unfortunately, according to the author, Dutch law does not authorise for newborns what it does authorise for consenting adults who are in the same circumstances. Indeed, according to him, it should be possible to accept euthanasia for newborns under certain strictly enforced conditions.



Glossary²¹

Anencephaly

Anencephaly is a congenital malformation of the central nervous system resulting from the absence of normal neural tube closure at the cranial end of the developing brain, usually between the 23rd and 26th day of pregnancy. This malformation causes partial or complete absence of the brain, skull, and scalp. A foetus with this malformation has no fore-brain, and has neither the capacity to think nor to make coordinated movement. The brain tissue that remains is often exposed due to the lack of skull and scalp. These problems are sometimes associated with the absence of spinal cord (*amyelencephalia*). Newborns with *anencephaly* are usually deaf, blind, unaware of their surroundings, and unable to feel pain. Generally, newborns are not viable if there is a complete absence of the brain, but they can live for several days if parts of the brain are present, notably when the brainstem is able to support breathing and cardiovascular activity.

Epidermolysis bullosa

Epidermolysis bullosa is an inherited connective tissue disease causing blisters in the skin and mucosal membranes, with an incidence of 1/50,000. It is a result of a defect in anchoring between the dermis and epidermis, causing friction and skin fragility. Its severity ranges from mild to lethal.

Hypoplasia

This is a general term introduced in 1870 by Virchow from the Greek *hypo* “under” and *plasis/plasein* “form/formation”. It means arrested or insufficient development of a tissue or organ. Most of the causes of *hypoplasia* are genetic diseases, but it can also result from toxicological phenomena (e.g., exposure of the embryo *in utero* to certain chemicals or teratogenic drugs).

Hypoxemia

Hypoxemia is an abnormally low level of oxygen in the blood.

Hypoxia

Hypoxia is a term from the Greek *hypo* “under” and *oxus* “oxygen”. It means a mismatch between the oxygen requirements of tissue and the amount of oxygen received. It may be the result of *hypoxemia* (low level of oxygen in the blood).

Spina bifida

Spina bifida is a type of malformation of the posterior arches of the vertebrae, which is characterised by a fissure or “bifid” line (split) of the spine; the fissure thus created can make it possible for a sac filled with cephalorachidian fluid (*meningocele*) and sometimes with nervous tissue (*myelomeningocele*) to protrude as a hernia of the spinal cord²².

The conditions

The conditions outlined in the *Groningen Protocol* are as follows:

- 1- The diagnosis and prognosis are both unmistakeable
- 2- Irremediable and unbearable suffering are present
- 3- The parents have been informed beforehand and have consented
- 4- The medical diagnosis and prognosis have received independent confirmation by at least one doctor
- 5- The procedure to be followed conforms to medical standards
- 6- A report is submitted to an authority responsible for verifying adherence to the procedure

The procedure

To ensure that the procedure is followed as closely as possible, the *Protocol* describes the steps of the procedure in detail, particularly those regarding informed consent procedures.

1- Concerning the diagnosis and the prognosis:

- A description of all relevant medical data and investigations used to establish the diagnosis.
- The list of all those who participated in the process, with all opinions expressed and the final consensus.
- A description of the method used to establish the prognosis for the patient's health in the long term.
- A description of the method used to establish the degree of suffering and life expectancy.
- A description of the treatments that the patient underwent before the decision on euthanasia, and their results.

2- The decision to practice euthanasia

- The name of the person who initiated the discussion and the time that discussion started.
- A list of the points that were taken into consideration and which led to the decision.
- A list of all persons who participated in the decision-making process, all opinions expressed, and the final consensus.
- A description of the method used to inform the parents and a statement of their opinion.

3- Consultation

- A list of the doctor(s) who gave their independent opinion(s) with their name(s) and specialisation(s).
- A description of the results of their case review and their recommendations.

4- Implementation

- A description of the procedure followed (time, place, participants and administration of the product).
- A statement of the reasons for choosing to practice euthanasia.

5- Steps to take after death

- A description of the findings from the legal authority.
- A description of the method used to report the death by euthanasia to the legal authorities.
- A description of the method used to treat and support the parents.
- A description of planned follow-up, including case review, post-mortem examination, and genetic counseling.

Legal status

In the Netherlands, euthanasia ("actieve levensbeëindiging" [active termination of life]) is authorised, under certain conditions, for persons aged 18 and over who apply for it. For children between 12 and 16 years of age, euthanasia is also authorised, if their parents consent. If the children are between 16 and 18 years old, the parents be informed of their child's request and its status, but if there is disagreement, the final decision rests with the minor.

The *Groningen Protocol* was drafted without reference to any legal framework. Written in September 2004 at the University Hospital of Groningen in concert with the local Prosecution Office, it was authorised as a national guideline by the *Nederlandse Vereniging voor Kindergeneeskunde* [Dutch Association for Paediatric Care] in July 2005. As it has not been written into law, it does not fully protect doctors. However, there has, in fact, never been a prosecution.

Statistics

During the seven years that preceded the publication by Professor Verhagen on the *Groningen Protocol* (2005), 22 cases of neonatal euthanasia were reviewed by the Dutch legal authorities. In no case was prosecution undertaken. At the beginning of the 1990s, two doctors who had euthanised newborns were prosecuted, but in both cases, the court ruled that their acts were consistent with “good medical practice”.

For the aforementioned 22 cases, Professor Verhagen provides the following details of the circumstances which, according to him, justified euthanasia:

	Number of cases	%
Extremely poor quality of life (suffering) in terms of functional handicap, pain, discomfort, poor prognosis and hopelessness	22	100%
Prospect of total dependency	22	100%
Prospect of inability to communicate	18	82%
Expected dependency on medical care	17	77%
Long life expectancy/ *	13	59%
* According to Professor Verhagen, the other criteria should be given greater weight if the patient has a longer life expectancy.		

The interpretation of these 22 cases by Professor Verhagen has attracted serious criticism, however (see below).

It's always hard to obtain statistics on practices that are considered illegal. Data are bound to be sparse and questionable. According to Professor Verhagen, 15 to 20 newborns are euthanised each year in the Netherlands. In addition, it seems clear that newborns are euthanised in other European countries as well. This fact was confirmed via an anonymous survey of paediatricians from several countries conducted by the European workgroup *Euronic* and published in *The Lancet*². Thus, 73 % of French neonatologists have apparently admitted to administering products to newborns with the inten-

tion of ending their lives. The related percentage is apparently 47% in the Netherlands, but falls to 4% in Germany and the United Kingdom and to 2% in Spain, Sweden and Italy.

There is no obvious explanation for the high percentages of euthanasia *per se* in France and the Netherlands. The study emphasises, however, that the absence of a clear definition of euthanasia is a problem, even though question 6 on the survey questionnaire leaves no room for doubt: doctors must report whether they have decided, singly or in a group, “[to administer substances in order to end a patient’s life]”. From an ethical and legal point of view, a large difference exists between the administration of analgesics **with the intention of alleviating suffering**, at a risk of prematurely inducing death (an indirect consequence and therefore, unintentional as such), and the administration of products **with the intention of inducing death**. Nonetheless, it is important to recognise that, in reality, the difference is sometimes minimal, and that it is hard to discern the true intentions of doctors in this matter.

According to a study on Flanders³ which covers the deaths of 253 newborns in 1999 and 2000, a decision to end a life was apparently taken in 194 cases, resulting in 117 deaths soon afterwards and 77 later on. Lethal products were apparently administered in 15 cases in the former category, and in 2 cases for the latter.



The criticisms

Up until now, no protocol similar to that of Groningen has been admitted in any other country that authorises euthanasia. The *Groningen Protocol* has attracted considerable criticism, and some people question the relevance of the conditions set out by its author.

1- Unmistakeable diagnosis and prognosis

Making a prognosis on the “future quality of life” of the newborn implies making a judgment about the value of the life that awaits the infant. In an opinion issued in 2009, the Ethics Committee of the health care network *Zorgnet Vlaanderen*⁴ protested against judgments pronounced on sick and disabled people. In the eyes of this Committee, these people have neither more nor less value and dignity than anyone else. Dignity is intrinsic to all human beings. Moreover, it turns out that, while growing up, the people concerned attach a greater importance to their life than their doctors attributed to it just after their birth. It then follows, in keeping with the principle of autonomy, that neither doctors nor parents are entitled to take a decision that will lead to killing a newborn who suffers from a severe illness.

Also, in one of their studies, Danièle Moyse and Nicole Diederich show that people without disabilities evaluate the quality of life of the disabled as lower than do people who have the disabilities themselves⁵.

Laurence Henry, author of a book on euthanasia of infants⁶, admits that even when a diagnosis is unequivocal, the greatest caution is nonetheless required in making the prognosis, especially in paediatrics, and in particular with regard to cerebral lesions. This call for prudence applies to both the doctor issuing the first prognosis and the doctor who is consulted later to confirm it. Medicine, far from being an exact science, requires a certain degree of humility in this matter.

In addition, the fact that the majority of the examples cited by Professor Verhagen were children with *spina bifida* has sparked strong reactions from specialists in this disease. According to Professor

De Jong of Sophia Children's Hospital, who has treated many children with this disease, they “[are not ‘terminally ill’ and do have ‘prospects of a future’. In these end-of-life decisions, ‘quality of life judgments’ should not be applied.’ (...) There is no reason to actively terminate the lives of these newborns]”⁷. Similarly, in 2006, the *International Federation for Spina Bifida and Hydrocephalus* took the position that:

- *All children with spina bifida or hydrocephalus have the right to life and to all treatments that can improve their quality of life or prevent future discomfort. Actively ending the life of newborns with spina bifida or hydrocephalus on the basis of expected quality of life should not be permitted.*
- *Spina bifida should never be a reason for not administering a treatment that aims to save or improve the life of newborns.*
- *It is important to emphasise that diversity enriches society and that all human beings can contribute to our living together as long as their differences are accepted and the means provided to promote their inclusion. A society's degree of civilisation can be measured as a function of its care for its weakest members.*
- *Erroneous societal assumptions about the quality of life of people with spina bifida and/or hydrocephalus should not be used to justify active termination of their life on the grounds of disability*⁸.



2- Incurable and unbearable suffering

In a critical article on this topic, published in 2008 in the medical journal *The Lancet*⁹, Professor Eric Kodish is particularly critical of the *Groningen Protocol*. According to him, it in fact violates several basic principles of medical ethics. One of his criticisms specifically addresses Professor Verhagen's acceptance that it is possible to detect unbearable suffering in a person who is unable to communicate. According to Professor Kodish, this is an extremely subjective matter. Serge Vanden Eijnden and Dana Martinovici follow the same line of thinking. According to them, the direct application of the concept of an adult's "unbearable suffering" to the newborn is one of the main flaws of the Protocol¹⁰. Indeed, drawing on an opinion from the *Nuffield Council on Bioethics*, they propose that one can never be certain of the "unbearable" nature of suffering for the newborn; so this involves the risk of letting children die whose pain could be alleviated¹¹. This does not mean that we should not treat pain with analgesics or other means. However, it does mean that suffering should never be viewed as a valid criterion for proceeding to euthanasia.

By the same token, according to Laurence Henry, when one broaches the subject of suffering, it is important to agree on what is meant by pain. Nowadays, when referring to the suffering of a patient, the medical community refers to the concept of *Total Pain*, which associates the sensory experience of pain with psycho-affective, socio-familial and spiritual components. Now, in a newborn, it is legitimate to ask if this concept is valid, for the concept rests on past experience of pain that the newborn does not have. While it is evident that a newborn can feel pain very intensely, it seems impossible to evaluate the other aspects of its suffering through the eyes of an adult. Moreover, we should not forget that the child will never have experienced life without illness or handicap. Evaluation by outsiders, who imagine what they would feel if they had the same disease, is bound to be distorted.

3- Informed parental consent

According to Professor Kodish, parental consent is a very ambiguous criterion. One applies it as though children were the property of their parents. However, there are cases where the physician is required to protect a child from its parents. One can never equate parental consent with that of adults who decides for themselves.

Laurence Henry also asks—and the question seems legitimate—whether parents will consent to the death of their child, with the passivity that that can sometimes imply, because no other option is proposed to them, or whether they will take a more active part in the decision. What arguments will be presented to parents, what words will be used to make them comply with the decision to terminate the life of their child?

The International Federation for Spina Bifida and Hydrocephalus states, for its part, that for children with these pathological conditions, "[the advice given to parents should be such as to comfort them and cover all aspects of the life of a child suffering from these diseases, as well as all recent scientific advances that have significantly improved their quality of life]". The Ethics Committee of the Flemish healthcare network *Zorgnet Vlaanderen* echoes this view by affirming that neither caregivers nor parents have the right to decide to end the life of a child; rather, their role must be to seek as good a life as possible for the child.

Ultimately, the parents' response is largely influenced by the way in which the situation is presented to them, if we leave out of account their emotional distress. According to A.B. Jotkowitz and S. Glick, parents rely on the advice of experts who predict a future situation which the parents have obviously never experienced themselves¹². This raises the question of the value of their consent to their child's death.

4- Confirmation of the medical diagnosis and prognosis by at least one independent doctor

As already stated, the initial prognosis can be made only with the greatest reservations. Logically, the same holds true for its confirmation; indeed, the more so, since, in these circumstances, this confirmation by a second doctor sounds like a decisive verdict. Crucially, nothing is said about how this doctor is chosen. This second opinion will decide the baby's fate. It will therefore be tempting for each person to try to influence the final decision, whatever it may be, through this choice.

We should not forget either, as A.B. Jotkowitz and S. Glick state in the article cited above, that both the first and the second doctors may be biased by the prospect of taking on patients suffering from severe disabilities or chronic illnesses for long periods.



5- A procedure that conforms to medical standards

Both Laurence Henry and Professor Kodish are perplexed by this criterion. Indeed, it seems rather paradoxical to require that euthanasia be performed in conformity with “good practice” in the field, when throughout the world it is an illegal practice.

In addition, we might ask whether establishing a detailed process with specific control points for performing euthanasia of a newborn has the sole purpose of ensuring that the act is performed “according to the rules”. Does it not also aim, by its mechanical nature, to lighten the emotional and ethical burden which such a practice entails? The question deserves some thought.

6- Transmission of a report to an authority responsible for verifying conformity to the procedure

As is the case for euthanasia of adults in countries where it has been decriminalised, this condition rings hollow. Checking the validity of an irreversible act after it has been carried out makes no sense. And what would be the value of any compensation when the life of a child is at stake?

Besides, euthanasia of newborns remains illegal in the Netherlands. The temptation is therefore great for doctors who practice it to deliberately omit this step. Thus, in an interview granted in March 2013 to the Dutch newspaper, *NRC Handelsblad*¹³, the chairman of the review committee was surprised that no reports had been submitted in 2012 and 2013, although it was more than likely that newborns had been euthanised.

Towards “post-natal abortion”?

In an article published in 2013¹⁴, Professor Verhaagen returns to this matter. In particular, he intends to respond to the argument of the “slippery slope” advanced by opponents of euthanasia of newborns, who believe that once the door is opened, the number of such operations may increase due to a weakening of standards.

The author of the *Groningen Protocol* responds by citing studies of deaths in the neonatal intensive care units in the Netherlands between 2001 and 2010. Ninety-five percent of the deaths in these units followed a decision to stop treatment.

Sixty percent of the cases concerned babies whose condition was unstable and whose death was inevitable; in 40% of cases, the decision was taken with reference to an unfavourable prognosis for quality of life. The number of euthanasia cases reported to be in conformity with the *Groningen Protocol* fell over 5 years from 15 to 2. All of these were children with *epidermolysis bullosa* (see the glossary). In contrast, the number of euthanasia cases of children with *spina bifida* fell from 15 to 0. The explanation is simple: progress has been made in screening, such that most fetuses with this disease were aborted, as confirmed by the statistics on abortion.

In addition, only declared cases of euthanasia are counted in the statistics presented. Treatments that could have been performed in borderline cases probably were not reported because (it's worth remembering) doctors remain susceptible to prosecution. The *Groningen Protocol* imposes strict conditions on physicians. Those who do not comply strictly with the law no doubt prefer their operations to proceed unnoticed.

The connection between euthanasia of newborns and abortion is also worth thinking about. A provocative article published by Alberto Giubilini and Francesca Minerva in the *Journal of Medical Ethics* is very revealing on this point¹⁵. The two authors who are not doctors, but rather philosophers, believe that it should be permissible to euthanise newborns whose condition would have "justified" an abortion. The proposal is applicable not only to children with a serious illness that causes unbearable suffering or drastically alters their expected quality of life, but also to all children with a severe disability. The fact that these severely disabled children can lead a happy life is not, in their eyes, a valid objection, insofar as these children may represent a burden that is judged to be unbearable for their parents, family or society.

For these cases, the authors seem to prefer the expression "post-natal abortion", for although, according to them, euthanasia is practiced in the interest of the patient, that is obviously not the case with abortion.

According to these authors, putting newborns to death is not morally reprehensible inasmuch as they are not "persons" in the sense of "subjects having the right to live". According to them, a person is in effect defined as an individual capable of assigning a value to his or her own existence, in such a way that privation of this existence constitutes a loss for him or her. The newborn is thus only considered to be a "potential person". These two authors obviously draw their inspiration from a very debatable utilitarian concept—a premise advanced as long as 30 years ago by philosophers such as Michael Tooley¹⁶ or Joseph Fletcher¹⁷—by virtue of which human beings have no value in and of themselves, but only in function of the utility that each one can offer either to himself/herself or to others (For further information, refer to the EIB Dossier: *Questions d'infanticides: bruits d'euthanasie d'enfants handicapés* [On infanticide: whispers about euthanasia of handicapped children]¹⁸).

As one can imagine, this article rightly attracted many indignant reactions. However, it has the merit of showing that the distinction between abortion and euthanasia of newborns is not as clear as some authors would like us to believe. If we consider the child in the womb not to be a complete person, it is not easy to then argue that the baby who has just been born has now become one. The one is neither more conscious nor more autonomous than the other.

Withholding futile medical care and newborns

The *Groningen Protocol*, as we have seen, takes a clear stance in favour of euthanasia proper, under certain conditions: for newborns with serious illnesses that cause unbearable suffering with no hope of remission, or that entail a significantly diminished quality of life. It should, however, be remembered that this practice has not been legalised in any country, and that, even in the Netherlands, it is merely tolerated.

It therefore seems appropriate to consider the conditions under which treatments provided to newborns with severe and incurable diseases may be terminated. Enormous progress has been made in recent decades in this field, which has enabled a large number of newborns to survive with an acceptable quality of life. If there is a decent chance of recovery, obviously there is no reason to hesitate to keep the newborn alive. But what about when the chance of survival is slim or the risk of sensory, motor or cognitive sequelae is high? In other words, how should we apply to newborns our universally accepted ethical principles related to withholding futile medical care? Although the principle is clear, its application is always a sensitive matter. It is up to all concerned—patient, medical team, and family—to judge, case by case, if the conditions are met for not starting, or for stopping, treatment and for taking steps to set up palliative care so that the natural process of dying may take its course as peacefully as possible.

In its 1999 opinion article, the Ethics Committee of the “*Zorgnet Vlaanderen*” healthcare network (see above) clearly took a stance against any futile medical care. It held that not starting, or not extending, treatment for a newborn with a serious illness may be morally acceptable or even constitute a moral duty. Under this view, treatment is justified medically only if it confers a benefit to the patient and if the suffering or discomfort it causes is proportional to the benefits that can be expected.

Still, we need to know what is meant by “treatment”. We must in fact clearly distinguish between “treatment” and “care”. “Care” generally designates fundamental actions to maintain cleanliness, warmth, nutrition, hydration and breathing, and thus to ensure that life continues. From birth, a child must receive this kind of care, even if its life expectancy is only a few hours. “Treatment”, which includes medical or paramedical acts (such as respiratory physiotherapy) is to be implemented only if it is considered really useful, proportional, timely and likely to improve the condition of the newborn.

According to the *American Pediatric Academy*, which has looked in depth at the problem of cessation of artificial nutrition or hydration of newborns with serious diseases¹⁹, if the child is able to eat and drink normally, nutrition and hydration are not a treatment, but rather a form of care. It follows that ending this care is not consistent with medical ethics, whatever the status of the newborn. This does not hold true if the newborn is fed artificially, for example, by means of a feeding tube or injections. The *American Pediatric Academy* views that circumstance as treatment and finds that there is cause to apply the general principle, according to which life may be terminated if the inconvenience to the patient exceeds the advantage he or she will gain. For example, it considers this to be the case if the child has no current or future possibility of interacting with its environment, notably in cases of *anencephaly* or persistent vegetative state.

Nevertheless, we would like to express serious reservations about nutrition being considered a treatment, even if it is artificially administered. Although it seems to us legitimate to stop nutrition at the very end of life, when it actually causes more harm than good to the patient whose death will occur anyway in the short term, we will never find it acceptable to stop nutrition in order to put an end to the patient’s life.

In conclusion

The *Groningen Protocol* stems from a utilitarian view which is based on an assessment that remains dubious, that of the future quality of life of a newborn. It therefore presupposes that it is possible to make an objective judgment on the value of a developing life. As A.B. Jotkowitz and S. Glick rightly say, “[Who gave doctors the right to judge the quality of life and to practice euthanasia on that basis? Children must be protected by society, whatever their medical condition, and should not be condemned to death.]”

Even if one fully agrees with the principle of withholding futile medical care, shouldn't we reaffirm that palliative care for these specific situations takes into account better the humanity of the suffering newborn baby and that of its parents?

“Of course the pain of knowing that one will lose one's child remains, but knowing that one can accompany the child and share whatever moments remain of its life gives parents a chance to be parents and to be there for them till the end.”²⁰

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 22. V. Fattorusso-O. Ritter : *Vademecum clinique*, Paris 1985, p. 688.

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