



# Neonatal euthanasia: A claim for an immoral law

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## Abstract

Active ending of the life of a newborn baby is a crime. Yet its clandestine practise is a reality in several European countries. In this paper, we defend the necessity to institute a proper legal frame for what we define as active neonatal euthanasia. The only legal attempt so far, the Dutch Groningen protocol, is not satisfactory. We critically analyse this protocol, as well as several other clinical practises and philosophical stances. Furthermore, we have tried to integrate our opinions as clinicians into a law project, with the purpose of pinpointing several issues, specific of perinatal that should be addressed by such a law. In conclusion, we argue that the legalisation of neonatal euthanasia under exceptional circumstances is the only way to avoid all the “well-intentioned” malpractices associated with ending life at the very dawn of it.

## Keywords

Neonatal active euthanasia, Groningen protocol, postnatal abortion, decision making

## Sociocultural context

All over the world, active ending of life of newborn babies is considered a crime. The Nuffield Council on Bioethics states that this should not be done, no matter how serious the condition of the baby.<sup>1</sup> Yet, the EURONIC study revealed that, in France and the Netherlands, more than half of the interviewed neonatologists anonymously confessed that “they had ever been involved in a decision of active euthanasia”.<sup>2</sup> In France, palliative care was legalised in 2005 but any attempt to deliberately end the life of a person remains a criminal act. The EURONIC study also attested that French neonatologists are not in favour of “more law than now” and prefer to be “free to exceptionally transgress” the law. The latest report of the French National Ethics Advisory Committee on neonatal resuscitation is supporting this idea of an ethically justified transgression of the law in hopeless situations,<sup>3</sup> although it has been criticised for putting physicians in an ambiguous position because it bears no legal weight.<sup>4</sup> In the Netherlands, both palliative care and – since 2002 – active voluntary euthanasia are legal for adult patients. It is also the only nation worldwide to have developed – in 2002 – a protocol, the so-called “Groningen protocol” that aims helping to not prosecute neonatal euthanasia under exceptional circumstances.<sup>5</sup> In between, in Belgium, both palliative care and active voluntary euthanasia for adult patients are legalised

since 2002. In 2010, a law project was submitted at the House of Representatives, in the attempt to extend active euthanasia to children, including those who do not have the faculty of discernment – such as newborns.<sup>6</sup>

We will discuss the implication of the presence or the absence of a legal frame for neonatal euthanasia in those countries where, despite still being highly controversial, it has gained some sociocultural acceptance.

## What do we call “neonatal euthanasia”?

Before starting any discussion on this topic, it is important to underline the fact that we shall be addressing active neonatal euthanasia, which is the administration of drugs, most often opioids and/or sedatives, with the intention of ending within hours the life of a neonate who would have likely survived months or years without these drugs. We will not argue on the specific term of “euthanasia” which we consider appropriate, as

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referring to a “good death” without considering the will capacity of the patient.

We are not talking about the potential double effect associated with the relief of pain by opioids as a palliative care measure (as in refractory hypoxemia, decompensated metabolic disease, etc.), nor about withholding life-sustaining treatment (such as not performing palliative cardiac surgery for hypoplastic left heart syndrome or dialysis for severe renal dysplasia), not even about withdrawing life-sustaining treatment (such as extubating an extreme premature with severe intraventricular haemorrhage), all measures which might accelerate death. We believe that all these dramatic situations can or could be adequately managed by means of genuine neonatal palliative care, which aims at avoiding unreasonable obstinacy and which is now well integrated in most neonatal intensive care units (NICUs).<sup>7</sup>

The deepest controversy on active neonatal euthanasia concerns those newborn babies whose vital functions are intact and whose degree of discomfort does not require potentially life-threatening drugs, but whose prognosis is perceived so hopeless that the question of ending their life as the “least worst alternative” might arise (such as severely asphyxiated babies who have recovered their vital functions but whose brains are severely damaged, babies with genetic disease which would be lethal within months such as spinal muscular atrophy type III or trisomy 13, etc.).

### **Are there any moral or ethical grounds ever justifying neonatal euthanasia?**

On one hand, many philosophers absolutely condemn any form of euthanasia, based on the sacrosanct value of human life. Besides, some authors believe that killing a baby will always be morally unsupportable.<sup>8</sup> They argue that even if relieving the unbearable suffering of a neonate could be condoned, the “unbearable” quality of the suffering – which is intrinsically subjective – can never be ensured. This would imply the risk of making die some babies whose suffering and/or pain could be alleviated, a morally unacceptable choice according to these authors.

On the other hand, other authors have recently argued that neonates – despite being individual human beings – are not yet persons, in the sense of individuals who are able to make any aim and conceive their own future.<sup>9</sup> Subsequently, depriving them of a future – i.e. painlessly killing them – could not be harmful to them. The definition of personhood and its ontology is indeed the key to the moral debate on abortion and infanticide, because it determines the moral status of the foetus and the newborn baby. If we consider that both of them are non-persons, then late abortion and

neonatal euthanasia are morally equivalent and equally defensible. This idea had actually been advanced more than 30 years ago by philosophers such as Michael Tooley, or Joseph Fletcher who has already described neonatal euthanasia as “postnatal abortion”.<sup>10,11</sup>

This concept that newborn babies – as non-persons – lack the “right to live”, shockingly contradicts lay intuition. Different authors have opposed to this paradox, the concept that neonates are “potential persons”. Yet philosophers do not agree on the intrinsic moral value conferred by personhood potentiality. H Tristram Engelhardt proposed to attribute the status of “person in a social sense” to human beings lacking essential capacities of moral agents, such as newborn babies.<sup>12</sup> This argument acknowledges no duties but only rights to neonates, in particular the right to be raised and protected as weakest members of the society. Yet it is mainly an utilitarian argument, which aims at supporting important virtues such as sympathy and care for human life, securing child rearing, etc. It does not preclude infanticide in exceptional circumstances, such as for severely defective newborns.

The lively debate on neonatal euthanasia reflects these conflicting moral considerations among others.

### **Neonatal euthanasia and the law today**

Infanticide is nowadays largely condemned from a moral point of view, which has been translated into similar legal norms across nations, whatever the religious background.

The Netherlands is the only country where active neonatal euthanasia is overtly declared by physicians to justice. The Groningen protocol has been developed by physicians and attorneys in order to help the Ministry of Justice to assess whether the procedure followed meets the criteria for good medical practice, in which case they will not prosecute.<sup>5</sup> This unique legal attempt is remarkable, even if only a minority of cases are reported (3 reported cases per year compared to an estimated 15–20 actual ones).<sup>5</sup> Any moral consideration apart, one of the main flaws of this protocol is to have literally transposed the fundamental notion of “unbearable suffering” from adults to neonates. “Constant, unbearable and unrelievable, physical or psychological, suffering” is indeed the keystone of the law for adult patients, legitimating the right of patients to autonomously decide of their life and death in view of their own quality of life. Yet most of the neonates we are talking about are not experiencing pain – as any pain scale would objectify – when the question of ending their life “in their best interest” arises. Are they suffering? Are they willing to die? Common sense of any neutral observer will answer no. Even more, long term self-report studies on quality of life do not

necessarily confirm that major disabilities are associated with major suffering.<sup>13</sup> So why does the Dutch protocol insist on the necessity to assess and confirm the “unbearable suffering” of the child? First, because it refers directly to adult euthanasia which is legally and culturally accepted in the Netherlands. Second, because unbearable suffering calls for mercy, which for most people is the only moral value able to counterbalance the burden of immorality borne by infanticide. When we are facing a clinical situation that we perceive as hopeless, besides all our medical expertise, we tend to project our own despair onto the baby and his family. Inevitably, we add our own value of life. This fair, complex, psychological process builds up the impression of “unbearable suffering”, which is in reality poorly linked to the actual condition of the baby. This conceptualization process varies not only between individuals but also across continents, as it is deeply rooted in the sociocultural system in which we operate.<sup>14</sup> That’s why the notion of unbearable suffering is the most difficult to transpose into legal norms, in the context of perinatality.

The confusion with adult euthanasia is even more striking in the current Belgian law project. Here senators imagine simply adding one extra-article to the existing law for adult patients. This “3bis” article would specify the exclusive conditions for neonatal euthanasia: the demand would have to come from the parents, the role of the general practitioner would have to be endorsed by a medical team, a rapid decision might be justified by the clinical condition of a premature baby.<sup>6</sup> The lack of scientific background of this legal project is as troubling as the range of possible abuses it would allow. The specificity of the perinatal context is again completely overlooked.

### **Why should we legalise neonatal euthanasia?**

It would be unrealistic, at least in France, Belgium and the Netherlands, to believe that clandestine neonatal euthanasia does not exist and that neonatal deaths are only due to overwhelming disease or to double effect of bona fide palliative care. Undeclared neonatal euthanasia will probably continue to exist whatever the legal context, just the same as illegal unsafe abortions do. We might see this as a proof of the moral decline of our society, encouraged by the already existing laws legalising adult euthanasia or late abortion, or we could simply admit that these outlawed practises, performed by physicians all over the world, are merely the reflect of human distress in exceptional but unfortunately recurrent situations.<sup>15</sup>

In addition to its commonly perceived immorality, the criminal status of neonatal euthanasia leads to the

denial of the true intention of killing, which remains hidden behind some medical acts. This denial or at least the lack of transparency associated with these deaths has many negative consequences. First, this prevents any public scrutiny, any societal reflexion about an existing reality which stays confined in the secrecy of hospitals. Second, it impedes every effort in clinical practice to appropriately reach an ethically justified decision regarding the hypothetical acceleration of death of a newborn.

Except maybe in the Netherlands, the intention of neonatal euthanasia is never clearly shared with the parents, nor clearly expressed between caregivers. It has been showed that sharing decision-making with the parents is likely to have the least negative impact on long-term grief.<sup>16</sup> But is it desirable or even possible to share the true decision of killing a baby with his parents? Several studies have shown that most parents claim their will to be involved in end of life decision about their child.<sup>17,18</sup> Yet these studies were conducted in countries where neonatal euthanasia could not be overtly discussed, because it is illegal. Illegality certainly does not help to study the best doctor–parents relationship in such decision-making processes, nor to understand which is the best way to prevent long-term grief. In this context, caricatural paternalism remains the only alternative.

It is worth noting that, independently of the degree of autonomy we want to give to the parents, clinical ethical dilemmas are directly linked to the degree of certainty or uncertainty of the prognosis we give, in other words to medical authority.<sup>14</sup> In France, neonatologists tend to skirt stressful ethical dilemmas when talking to the parents by overestimating the degree of certainty of dismal prognosis.<sup>14</sup> In US, JM Appel defends the idea that the medical staff is in the best position to decide whether a baby should be killed to alleviate his suffering whatever the parental point of view.<sup>19</sup> But can we trust caregivers to always reach the best compromise for every newborn in a dramatic situation? Trust physicians and nurses who themselves have limited training in how to guide a collegial dialogue to adequately reach an ethical conclusion, who themselves react according to their own feelings and values in front of the possible death of a neonate and who are potentially facing criminal prosecution for premeditated murder? We do not think so.

Should then the parents be the only judges in taking such a decision, as suggested recently by Giubilini and Minerva?<sup>9</sup> Clinicians are sometimes confronted with parental demands of euthanasia which they perceive as abusive. In the few countries where euthanasia is legal in adult patients, parents sometimes believe that they have the right to take such decisions. In these situations, the criminal status of child euthanasia still offers

the way out. But what would happen if a law allowing neonatal euthanasia did exist? Are parents in the best position to judge what is the best future for their child? Should they always benefit of the presumption of benevolence towards their child? Or are they rather in a conflict of interests regarding the future of their child when this latter means the burden of handicap? There is of course no definitive answer to such questions, but in Belgium and France the law on late abortion for foetal anomalies has already set legal boundaries in this regard. Beyond 14 weeks' gestation, two doctors (in Belgium) or a multidisciplinary team (in France), must agree that the foetus presents a disease of utmost severity, incurable at the time of diagnosis, in order to accept the demand of late abortion coming from the mother (or the parents), which follows or not a medical recommendation. So a medical consensus must be reached regarding the hopelessness of the situation, while the mother is (or the parents are) driving the demand of terminating life. The Dutch law on neonatal euthanasia adequately keeps this subtle balance between medical responsibility and parental autonomy, which is necessary – even though not sufficient – to prevent abuses as well as legitimate accusations of eugenism.

The French and Belgian abortion laws allow to terminate a pregnancy up to term if specific medical conditions are met. Having extended this possibility beyond the limit of viability allows to better observe the evolution of the suspected anomaly and to refine its diagnosis, before taking a critical decision. After birth, clinicians are sometimes constrained to hasten their decision in order not to miss “windows of legal opportunity”. Death following withdraw of respiratory support in a severely asphyxiated term baby can be considered as legally defined palliative care, while a few days later, when the baby would have recovered spontaneous breathing the only alternative to avoid future severe sequelae would be clandestine euthanasia. We think that a legislation on neonatal euthanasia could help in the same way to avoid this deleterious hypocrisy.

### **How should we legalise neonatal euthanasia?**

We believe that any legalization of neonatal euthanasia should be designed with the help of neonatologists, NICU nurses and clinical psychologists confronted to these ethical dilemmas. As discussed above, mere transposition of the euthanasia law from adult patients, which draws its legitimacy from the principle of the full respect for the patient's autonomy, is not satisfactory. Just as the mere transposition of the abortion law would be illegitimate and insufficient. We argue that a legal frame for neonatal euthanasia should rely both on

legal standards developed in adult patients and on legal principles worked up for prenatal situations.

We will describe hereafter the main lines of our law project on neonatal euthanasia (see the full text in Appendix 1).

#### **Article 1**

“Neonatal euthanasia” shall mean the act performed by a neonatologist, whereby the life of a newborn child is intentionally ended at the request of its parents, provided that such a request has been deemed legitimate and admissible by a specialist care team. (The terms “parents” and “newborn child” are further defined.)

#### **Article 2.1**

Any neonatologist having performed neonatal euthanasia shall not be deemed to have breached the law provided that they made certain that:

- the newborn child had a pathological condition or injury that was both particularly severe and recognised as being incurable at the time of diagnosis and was consequently in a hopeless medical condition combined with existing and/or future, physical and/or mental suffering that was deemed constant, unbearable and impossible to relieve;
- the request of the parents was formulated voluntarily, thoughtfully and repeatedly and was not the result of external pressure;
- the request was deemed legitimate and admissible by a care team; and
- they acted in accordance with the conditions and procedures defined by this Act.

The neonatologist should in all cases first:

1. Form a primary care team comprising at least, in addition to themselves, a second neonatologist, a paediatric nurse or a midwife, a social worker and a psychologist, as well as the mother's gynaecologist if they so wish.
2. Hold collegial meetings of the primary care team to discuss in full transparency (i) the degree of certainty of the diagnosis and prognosis of the pathology affecting the newborn child; (ii) any further therapeutic possibilities; (iii) the nature and consequences of any palliative care arrangements; and (iv) any prospects for adoption or placement in specialised institutional care. Each member of the care team shall express their opinion from the assumed point of view of the child – in terms of existing and/or future, physical and/or mental suffering, the ability



- to communicate and lead an independent live – and from the perceived point of view of the parents – in terms of their willingness and ability to bear the burden of a child with a severe and incurable disease.
3. Seek the opinion of a third doctor who shall confirm the degree of certainty of the diagnosis and prognosis.
  4. Inform the parents of the health condition and life expectancy of their newborn child, discuss with them any further therapeutic possibilities as well as the nature and consequences of any palliative care arrangements and the possibility of adoption or placement in specialised institutional care. They shall endeavour to emphasise the prognostic uncertainties. They shall bear in mind that their authority and their own convictions may significantly influence the opinion of the parents. They shall take time to listen to the parents's point of view with due respect for their ethical or philosophical tenets or religious beliefs. The conviction that the state of the newborn admits no reasonable solution other than euthanasia should be achieved jointly by the parents and the primary care team. The intentional nature of the act whereby the life of the newborn child is terminated cannot be concealed from the parents or in any way mistaken for palliative care. Death as final intent is made explicit using the terms "active ending of life" in the request form signed by the parents (see the informed request in Appendix 2);
  5. Confirm the enduring nature of the situation, the desire expressed repeatedly by the parents and the reiterated consent of the care team;
  6. Ensure that the parents, if they so wish, have had the opportunity to discuss the situation with any persons of their confidence, religious representative(s) if any or other individuals they may wish to meet.

### Article 2.3

Furthermore, if the neonatologist is of the opinion that constant, unbearable pain that is impossible to relieve is not immediately present and that death is clearly not a likely outcome in the near future, they should allow at least two weeks between the written request of the parents and the performance of euthanasia.

### Article 2.4

The request must be signed by the parents, by the neonatologist who is to perform euthanasia and by another representative of the care team (see Appendix 2). The parents or any member of the care team may withdraw their request or their support of the request, respectively, at any time.

### Article 3

After having performed an act of neonatal euthanasia, the neonatologist shall duly fill in and submit the declaration file to the Supervisory and Evaluation Commission, which is established to monitor the implementation of this Act.

(The composition of the Commission is defined in Article 4).

### Article 5

The Commission shall develop a declaration file to be filled in by doctors each time they perform a neonatal euthanasia. The first part of this document is confidential and shall be sealed. It shall contain the names of the newborn patient, the parents, the doctor, etc. The second section too shall be confidential and shall include the gender and date and place of birth of the newborn patient, the date, place and time of death, a statement of the pathological condition, the nature of the existing and/or future suffering that was deemed constant and unbearable, the factors used to ascertain that the request submitted by the parents was formulated voluntarily, thoughtfully and repeatedly, how euthanasia was performed, etc.

### Article 6

The Commission shall assess, based on the second section of the declaration file, whether euthanasia was performed in accordance with the conditions and procedure set out in this Act. If in doubt, the Commission may decide to lift the anonymity of the first section and may ask the doctor to submit all relevant evidences pertaining to the neonatal euthanasia. Where the Commission decides that the conditions have not been fulfilled, it shall refer the file to the Public prosecutor.

### Article 7

The Commission shall ensure that the involved neonatal wards receive annual supervision. Such supervision shall be provided by doctors, nurses, psychologists, experts in law, representative of parents, etc. Such supervision shall aim to improve collegial practice pertaining to ethical decision-making, communication with parents, bereavement counselling for parents and caregivers, etc.

### Article 8

The Commission draws up (a) a statistical report; (b) a report describing and reviewing the implementation of this Act; (c) recommendations, if any.

## Article 13

The request for neonatal euthanasia shall not be compelling. No doctor may be required to perform euthanasia. No other individual may be required to take part in euthanasia. No parent may be required to accept euthanasia of their child. Any consulted doctor – or care team – refusing to perform euthanasia shall be required to inform the parents in timely fashion and to explain to them the reasons for their refusal. Any doctor or care team refusing to act upon a parental request for neonatal euthanasia shall be required, upon request by the parents, to provide the medical record of the patient to another doctor indicated by the parents.

## Conclusion

Active neonatal euthanasia, defined as the act of deliberately accelerating the end of life of a newborn whose prognosis is doomed, is a reality in the Netherlands and a hidden reality in France, Belgium and probably many other countries.

It is true that considering neonatal euthanasia as an imprescriptible crime is likely less hazardous than taking the chance of enacting too simplistic a law, a law that would not take into account the specificity of perinatality. Yet we believe that our society should be able to give a proportionate legal dimension to this human ethical dilemma, whatever its intrinsic complexity.

We also believe that building a proper legal frame for neonatal euthanasia rather than absolutely condemning it is the only way to limit this practice to exceptional but unfortunately existing circumstances and to avoid any potential “well-intentioned” abuses.

The worldwide scandal raised by the Groningen protocol and by the more recent paper on “after-birth abortion” suggests that our society remains reluctant at the idea of legalising an act legitimately perceived as immoral. Yet we believe that it is time to bring this question out of the exclusive cenacle of medical expertise and to spark a true societal reflexion on this complex reality.

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## Appendix I

### Neonatal Euthanasia Act – Project

*Chapter I – General provisions. Article 1.* For the purposes of this Act, the term “neonatal euthanasia” shall mean the act performed by a neonatologist, whereby the life of a newborn child is intentionally ended at the request of its parents or guardians, provided that such a request has been deemed legitimate and admissible by a specialist care team. Where further used herein, the term “parents” shall mean parents or legal guardians, i.e. the legal custodians of the person and property of the child. Regardless the place where euthanasia, if any, is eventually performed, the term “newborn child” shall mean any child, whether newborn or not, hospitalised since birth.

*Chapter II – Conditions and procedure. Article 2.1.* Any neonatologist having performed neonatal euthanasia shall not be deemed to have breached the law provided that they made certain that:

- the newborn child had a pathological condition or injury that was both particularly severe and recognised as being incurable at the time of diagnosis and was consequently in a hopeless medical condition combined with existing and/or future, physical and/or mental suffering that was deemed constant, unbearable and impossible to relieve;
- the request of the parents was formulated voluntarily, thoughtfully and repeatedly and was not the result of external pressure;
- the request was deemed legitimate and admissible by a care team; and
- they acted in accordance with the conditions and procedures defined by this Act.

2.2. Without prejudice to any and all additional conditions specified by the neonatologist for their intervention, they should in all cases first:

1. Form a primary care team responsible for privileged contacts and dialogue with the parents and comprising at least, in addition to themselves, a second neonatologist, a paediatric nurse or a midwife, a social worker and a psychologist, as well as the mother’s gynaecologist if they so wish. Two members at least of the care team shall have specific expertise or accredited qualifications in ethics and perinatal palliative care.
2. Hold one or more collegial meetings of the primary care team with the purpose of discussing in full transparency (i) the degree of certainty attached to the diagnosis and prognosis of the pathology affecting the newborn child; (ii) any further therapeutic

possibilities; (iii) the nature and consequences of any palliative care arrangements; and (iv) any prospects for adoption or placement in specialised institutional care. Each member of the care team shall express their opinion from the assumed point of view of the child – in terms of present and/or future, physical and/or mental suffering, the ability to communicate and lead an independent life –, and from the perceived point of view of the parents – in terms of their willingness and ability to bear the burden of a child with a severe and incurable disease.

3. Seek the opinion of a third doctor, to whom the motives for consulting them have been clarified, as to the severe and incurable nature of the pathology. They must be independent with respect to both the patient, their parents and the care team; they must have specific competence with regard to the patient’s pathology. The consulted doctor shall inspect the medical record, examine the patient and confirm the degree of certainty of the diagnosis and prognosis in terms of existing and/or future, physical and/or mental suffering that is constant, unbearable and impossible to relieve. The consulted doctor shall draw up a report of their findings. The neonatologist in charge shall inform the parents of the outcomes of this consultation.
4. Inform the parents of the health condition and life expectancy of their newborn child, discuss with them any further therapeutic possibilities as well as the nature and consequences of any palliative care arrangements and the possibility of adoption or placement in specialised institutional care. They shall endeavour to emphasise the prognostic uncertainties underpinning the ethical dilemma and share them with the parents in all sincerity. They shall bear in mind that their authority as a doctor and their own convictions on the subject (or those of the care team), may significantly influence the opinion of the parents, either towards termination of life or therapeutic obstinacy. They shall see to the quality of the dialogue with the parents, taking time to listen to their point of view with due respect for their ethical or philosophical tenets or religious beliefs whilst personally refraining from applying external pressure on them. The conviction that the state of the newborn admits no reasonable solution other than euthanasia should be achieved jointly by the parents and the primary care team. An understanding of how to best share the burden of the decision to perform euthanasia should be reached jointly by the parents and the care team, according to each situation and each patient. The intentional nature of the act whereby the life of the newborn child is terminated cannot be concealed from the parents or in any way mistaken for palliative care. Death as final

intent is made explicit using the terms “active ending of life” in the request form signed by the parents. The choice of terms used during talks with the parents to describe any act whereby the life of the newborn child is ended – “euthanasia”, “terminal sedation”, “administration of painkillers and sedatives leading to death”, etc. – is left to the discretion of the doctor and care team.

5. Confirm the enduring nature of the situation, as well as the desire expressed repeatedly by the parents and the reiterated consent of the care team. To this end, they shall hold repeated talks with the parents and the care team at intervals which are reasonable with respect to the evolving condition of the newborn.
6. Ensure that the parents, if they so wish, have had the opportunity to discuss the situation and alternative care solutions with any persons of their confidence, religious representative(s) if any or other individuals they may wish to meet.

2.3. Furthermore, if the neonatologist believes that constant unbearable and unappeasable physical pain is not immediately present and that death is clearly not a likely outcome in the near future, they should allow at least two weeks between the written request of the parents and the performance of euthanasia on the newborn child.

2.4. The request must be submitted in writing. The document is written, dated and signed by the parents, by the neonatologist who is to perform euthanasia and by another representative of the care team. This document must be included in the medical file. The parents may withdraw their request at any time. Any member of the care team may also at any time withdraw their support for the request of the parents in an argued decision to be included in the medical file.

2.5. Any and all requests submitted by the parents as well as any and all steps taken by the doctor or care team and their outcomes, including all reports submitted by any and all consulted doctors shall regularly be included in the medical record of the patient.

*Chapter III – Declaration. Article 3.* Four working days at most from performing an act of neonatal euthanasia, the neonatologist shall duly fill in and submit to the Supervisory and Evaluation Commission discussed under Article 4 of this Act, the declaration file discussed under Article 5.

*Chapter IV – The Supervisory and Evaluation Commission. Article 4.1.* A Supervisory and Evaluation Commission, hereinafter called “the Commission”, is established with the purpose to monitor the implementation of this Act.

4.2. The Commission shall consist of 16 members appointed on the basis of their knowledge and expertise in matters pertaining to the competence of the Commission. Eight members shall be medical doctors, at least four of whom neonatologists with specific expertise or accredited qualifications in ethics and perinatal palliative care. Four members shall be professors of law with tenure in a Belgian university, or lawyers. Four members shall be from circles with responsibility for the issue of children with incurable diseases.

Membership of the Commission shall be incompatible with membership of a Legislative Assembly or of the Government.

The Commission shall validly deliberate only if at least two-thirds of its members are present.

4.3. The Commission shall set its own house rules.

*Article 5.* The Commission shall develop a declaration file to be filled in by doctors each time they perform a neonatal euthanasia.

This document shall be made up of two sections. The first part shall be sealed by the doctor. It shall contain the following information:

- (a) the surname, given names and home address of the newborn patient;
- (b) the surname, given names and home address of the parents or guardians;
- (c) the surname, given names, registration number and home address of the doctor;
- (d) the surname, given names, registration numbers and home addresses of all doctors consulted in connection with the request for neonatal euthanasia;
- (e) the surnames, given names, home addresses and occupation of any and all individuals consulted by the doctor and the dates of such consultations;

This first section shall be confidential. It shall be forwarded by the doctor to the Commission. It shall be disclosed only pursuant to a decision of the Commission and shall under no circumstances be used by the Commission as a basis to perform its assessment.

The second section shall be confidential as well and shall include the following information:

- (a) the gender and date and place of birth of the newborn patient;
- (b) the date, place and time of death;
- (c) a statement of the pathological condition(s) or injury presented by the patient;
- (d) the nature of the existing and/or future suffering that was deemed constant and unbearable;
- (e) the motives for describing this present and/or future suffering as impossible to relieve;



- (f) the factors used to ascertain that the request submitted by the parents was formulated voluntarily, thoughtfully and repeatedly and was not the result of external pressure;
- (g) the factors used to ascertain that the request was deemed legitimate and admissible by a care team;
- (h) whether death would clearly be a likely outcome in the near future;
- (i) the exact procedure followed by the doctor;
- (j) the qualifications of the doctor(s) consulted, the date(s) of such consultations and the resulting opinion(s);
- (k) the qualifications of any and all individuals consulted by the doctor, the care team or the parents and the dates of such consultations;
- (l) how euthanasia was performed and the means used.

*Article 6.* The Commission shall examine the declaration file duly filled in and transmitted by the doctor. The Commission shall assess, based on the second section of the declaration file, whether euthanasia was performed in accordance with the conditions and procedure set out in this Act. If in doubt, the Commission may decide by a simple majority vote to lift the anonymity requirement, whereupon it shall take cognisance of the first section of the declaration file. It may ask the doctor to submit all relevant evidence in the medical record pertaining to the neonatal euthanasia. The Commission shall decide within two months.

Where the Commission decides by a two-thirds majority that the conditions laid down in this Act have not been fulfilled, it shall refer the file to the Public prosecutor of the place where the patient died. Where lifting anonymity reveals facts or circumstances likely to affect the impartial and independent judgement of a member of the Commission, said member shall recuse themselves or may be disqualified from the examination of the case by the Commission.

*Article 7.* The Commission shall ensure that the neonatal wards of institutions named in any neonatal euthanasia declaration file receive annual supervision. Such supervision shall be provided by doctors, nurses and psychologists specialised in ethics and perinatal euthanasia as well as an expert in law and, if need be, a representative of bereaved parents of newborn children or parents of children with severe disabilities. Such supervision shall in particular aim to improve collegial practice pertaining to ethical decision-making, communication with parents, ways of supporting newborns at the end of their life, bereavement counselling for parents and caregivers. The Commission shall encourage research in the field of palliative care and neonatal euthanasia.

*Article 8.* The Commission draws up for the attention of the Legislative Chambers, first within two years

of enforcement of this Act and subsequently every two years:

- (a) a statistical report based on the data contained in the second section of the declaration files transmitted by doctors in accordance with Article 6;
- (b) a report describing and reviewing the implementation of this Act;
- (c) recommendations, if any, potentially leading to a legislative initiative and/or other measures regarding enforcement of this Act.

In carrying out these roles, the Commission may collect any and all useful information from miscellaneous authorities and institutions. All information gathered by the Commission is confidential. None of these documents may contain information disclosing the identity of any individual mentioned in the files transmitted by the Commission as part of the supervision discussed under Article 6.

The Commission may decide to disclose statistical and purely technical information, with the exception of any personal data, to academic research teams upon their reasoned request. The Commission may interview experts.

*Article 9.* The Commission is provided with an administrative framework to fulfil its statutory tasks. The number of the administrative staff shall be laid down in a Decree proposed by the Ministers with responsibility for public health and justice.

*Article 10.* The operating and staffing expenses of the Commission and supervisory teams as well as remuneration of its members shall be assigned in half, respectively, to the budgets of the Ministers with responsibility for justice and public health.

*Article 11.* Any individual contributing in whatever capacity to the implementation of this Act shall be under an obligation to respect the confidential nature of all information entrusted to them while discharging and in connection with, their duties.

*Article 12.* Within six months of submission of the first report, and Commission recommendations if any pursuant to Article 7, the Legislative Chambers shall hold a debate on this issue. Said period of six months shall be suspended for any period during which the Legislative Chambers are dissolved and/or in the absence of a Government having the confidence of the Legislative Chambers.

*Article 13.* The request for neonatal euthanasia provided for under Article 2 of this Act shall not be compelling. No doctor may be required to perform euthanasia. No other individual may be required to take part in euthanasia. No parent may be required to accept euthanasia of their child. Any consulted doctor – or care team – refusing to perform euthanasia

shall be required to inform the parents in timely fashion and to explain to them the reasons for their refusal. Where there is a medical motive for such refusal, said motive shall be included in the medical record of the patient.

Any doctor or care team refusing to act upon a parental request for neonatal euthanasia shall be required, upon request by the parents, to provide the medical record of the patient to another doctor indicated by the parents.

*Article 14.* A newborn child who died as a result of euthanasia performed in accordance with the conditions laid down in this Act shall be deemed to have died of natural causes for the purposes of performance of any and all contracts, in particular insurance contracts, to which they were a party.

## Appendix 2

### *Active ending of the life of a newborn child – Informed request*

In respect of (Surname, given name):

Date of birth: Place of birth:

I/We, the undersigned, declare:

having been informed of the health condition and life expectancy of my/our/the child, of any further therapeutic opportunities as well as of the nature and consequences of any palliative care arrangements and of the possibility of adoption or placement in specialised institutional care; having been heard with due respect for my/our ethical or philosophical tenets or religious beliefs; having had the opportunity, if I/we so wished, to discuss the situation and alternative care solutions with any person(s) of my/our confidence,

religious representative or other individual I/we wished to meet;

having achieved with the primary care team the conviction that the state of my/our/the newborn child admits no reasonable solution other than active ending of life in view of his/her condition, both particularly severe and incurable at the time of diagnosis, and combined with existing and/or future, physical and/or mental suffering that was deemed constant, unbearable and impossible to relieve;

that I/we formulate my/our request voluntarily, thoughtfully and repeatedly and that it is not the result of any pressure from outside or from the care team;

that I/we entrust responsibility for actively ending the life of my/our/the child with Dr, neonatologist, who will ensure compliance with relevant legislation and respect for the dignity of my/our/the child before and after his/her death.

The present declaration may be revoked at any time by any signatory prior to the death of the child.

Done at (place), on (date)

Date and signature of the mother of the child

Date and signature of the father of the child

Date and signature of the guardian(s) of the child (if applicable)

This declaration is deemed legitimate and admissible by:

Date and signature of the above-mentioned neonatologist in charge

Date and signature of a member of the care team who was involved in the decision to actively end the life of the child

*(Under each date and signature, please mention the surname, first name and capacity of the signatory)*