Considerations pertaining to neonatal life termination

Health Council of the Netherlands

Ethics and health monitoring report 2007

Centre for Ethics and Health

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Centre for Ethics and Health

To the State Secretary for Health, Welfare and Sport

The enclosed monitoring report deals with an emotive subject. A decision to terminate a life is made against a background of conflicting duties: the duty to alleviate or prevent suffering and the duty to preserve life. Opinion differs – in the Netherlands as elsewhere – as to how best reconcile these duties. It is all the more difficult to do so when the life in question is that of a neonate.

Last year, your predecessor and the then Minister of Justice set up the Central Expert Committee. The Committee's task is to review the care taken in individual cases of neonatal life termination and, by doing so, to clarify the requirements that apply in such cases. The establishment of this Committee is in line with the wider policy of seeking to enhance the quality of and care taken in end-of-life medical decision-making by facilitating discussion of the associated moral dilemmas.

The Health Council considers it important that the Expert Committee is given the opportunity to further develop and operationalise the care requirements on the basis of casuistry. In this monitoring report, the Council draws upon its particular scientific expertise to address a number of general points warranting attention in this field. Where a number of the relevant issues are concerned, the report recommends further standpoint definition. This is the case with regard to, for example, the acceptability of life termination outside the context of life-prolonging treatment, the desirability of making acute suffering a precondition for life termination and the basis on which a neonate's future quality of life may be assessed. Where certain other issues are concerned – including the incidence of life termination in practice, the way in which doctors assess neonates' health prospects and the fate of children born with very serious health problems – further scientific research is required.

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This document is a Centre for Ethics and Health monitoring report, published by the Health Council under the responsibility of the Standing Committee on Medical Ethics and Medical Law. An earlier draft was discussed by the Council's Medical Standing Committee.

Yours sincerely,

Professor J.A. Knottnerus
President
Health Council of the Netherlands

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Executive summary

Life termination causing or hastening death by the administration of a substance intended to have that effect – is a criminal offence in the Netherlands, which may constitute manslaughter or murder. However, under certain circumstances, a doctor who ends the life of a neonate may justify his/her action on the grounds of *force majeure* in the form of 'necessity'. Such justification is legally acceptable if the neonate's health status is such that the baby's suffering is or will become so severe that the doctor's duty to alleviate that suffering outweighs his/her duty to preserve the neonate's life.

It is believed that there are several dozen cases of neonatal life termination a year in the Netherlands. However, few such cases are reported – probably at least partly because of the uncertainty that exists concerning the conditions that must be satisfied in order to support a claim of *force majeure*. With a view to improving this situation, the State Secretary for Health, Welfare and Sport and the Minister of Justice set up an Expert Committee on 1 September 2006. This Committee's case review findings are taken into account by the Public Prosecutor when considering whether to prosecute doctors in life termination cases.

The State Secretary and Minister have indicated that the Expert Committee may conclude that due care was exercised in a life termination case if: on the basis of medical knowledge, the neonate's suffering was deemed to be intolerable and hopeless; the parents consented to the life termination; the doctor properly informed the parents about the diagnosis and prognosis and they collectively concluded that there was no other reasonable means of resolving the situation; the doctor consulted at least one other independent doctor or treatment team; and the life was terminated with appropriate medical care.

The Expert Committee's role is to further develop these criteria on the basis of casuistry and to operationalise them. This monitoring report addresses the general issues requiring attention in the context of that process. It describes several ethical dilemmas and indicates how medical science can help to resolve them.

In the Netherlands, there is a degree of consensus that neonatal life termination can sometimes be acceptable following a justifiable decision to withhold or withdraw treatment. Such a decision may be taken if treatment offers no prospect of survival or merely the prospect of survival with a very poor subsequent quality of life. If, under such circumstances, death is unlikely

to swiftly follow the withholding or withdrawal of treatment, thus giving rise to an emergency situation, life termination may be justified. The consensus that developed within the medical profession in the 1990s acquired a jurisprudential confirmation through the Prins and Kadijk cases.

More recently, the Groningen Protocol has been developed to cover a different situation, namely life termination outside the context of life-prolonging treatment. The protocol is based on the principle that a doctor has a special responsibility in relation to the subsequent life of a neonate that is suffering seriously or faces the prospect of a life characterised by serious suffering, regardless of whether life-prolonging treatment has previously been provided. The extent to which agreement exists on this point remains to be seen. The reports produced by or in conjunction with bodies representing the medical profession in the 1990s give no support to the idea of life termination outside the context of life-prolonging treatment, and no precedents have yet been created in case law. Furthermore, whether the State Secretary and the Minister deem such life termination acceptable remains to be seen. It is therefore desirable that a standpoint is defined on life termination outside the context of life-prolonging treatment and that the medical profession updates its earlier reports to cover this issue.

The Netherlands is one of the few countries where it is possible to approximate the incidence of neonatal life termination and indicate the circumstances under which it occurs. The relevant data come from evaluation studies into the practice and review of euthanasia. Nevertheless, we do not have a full picture of what takes place in the Netherlands. The reasons for this include the absence of a precise definition of life termination and a paucity of information concerning the particular features that characterise cases in which a substance is administered with the specific aim of shortening life.

In the context of the evaluation studies, a death was not classed as life termination if the administration of a substance merely hastened a death that was imminent following the withholding or withdrawal of life-supporting treatment. The latter approach is consistent with the view held by many doctors that, if death is inevitable within a matter of days or hours, the administration of a life-shortening substance constitutes palliative care, rather than life termination. Legally, however, the administration of a substance with the aim of hastening death is life termination even under such circumstances, and should accordingly be reported as such. The reporting of such deaths is also desirable for reasons of transparency. A medically induced death is not life termination only if the substance that brings it about is medically indicated, e.g. for the professionally justifiable management of pain. However, it is not clear how often the administration of a substance with the express intention of hastening death following a decision to withhold or withdraw treatment is medically indicated.

To obtain a good picture of the incidence of neonatal life termination, it is best to work on the basis of the legal definition of life termination: the administration of a substance with the aim of hastening death – either following a decision to withhold or withdraw (potentially) life-prolong-

ing treatment or under other circumstances. Furthermore, greater insight is needed into the features that characterise life termination cases, such as the health status of the neonate, the factors considered by the doctor and (where relevant) the nature, dosage and duration of the medication administered.

According to the assessment criteria laid down by the State Secretary and Minister, life termination can be acceptable in cases of hopeless and unbearable suffering. Such suffering may occur in two types of situation. First, where it is clear that the neonate will die before long, and the degree of suffering is felt to justify deliberately expediting the inevitable. Second, where the neonate could be kept alive, but there is no prospect of any improvement in the child's health sufficient to enable it to lead an independent life. However, the State Secretary and Minister also indicate that life termination may be justified only by acute suffering. It would therefore seem that, even in the second situation described, acute suffering must be present in order to warrant life termination.

Because acute suffering is the factor most likely to create an emergency situation, it would seem obvious at first sight that the presence of such suffering should be a precondition for life termination. However, arguments can be advanced for sometimes countenancing life termination where such suffering is not present. The reason being that a doctor has a duty not only to alleviate suffering resulting from an illness or abnormality, but also to prevent it. A situation could arise where a neonate faces the prospect of such serious suffering that the doctor believes that his/her duty to prevent that suffering outweighs his/her duty to preserve the infant's life. Under such circumstances, the doctor may consider it irresponsible to defer life termination until such time as the suffering becomes hopeless and unbearable. Furthermore, acute suffering is not a precondition for withholding or withdrawing treatment. If it is a precondition for life termination, a doctor who does not wish to be responsible for prolonging the life of a neonate with a bleak prognosis is liable to be cautious about initiating life-prolonging treatment.

In view of the foregoing, the Committee favours refinement of the principles underpinning the requirement that acute suffering be present.

Withholding or withdrawing life-prolonging treatment – and life termination – may be considered, the State Secretary and Minister indicate, if it is anticipated that the quality of the neonate's future life (as perceived by the neonate) is likely to be very poor. In the Netherlands, it is accepted that future quality of life may be assessed by taking account of the anticipated level of suffering, the neonate's life expectancy, the unpleasantness of the associated treatments, the scope for communication, the prospects for independence and the probable level of dependency on the medical care system. However, there remains no consensus regarding the application of this principle and the significance and weighting of the various criteria require further examination.

Furthermore, given the inherent value of life, it is desirable that the formulation of long-term health prognoses and the assessment of their functional significance for the neonate be evidence-based as far as possible. However, evidence is scarce. More research is therefore needed into the lives of children born with very serious health problems. It is also advisable that the medical profession should look into the possibility of using the findings of such research as the basis for developing guidelines on the formulation of decisions in connection with conditions of various types.

However, there is inevitably a degree of uncertainty attached to any assessment of a neonate's future quality of life. Consequently, doctors need to be cautious when considering either withholding/withdrawing life-prolonging treatment or life termination on the grounds of future life quality. This is not to diminish the ethical and legal principle that medical treatment that may not be expected to benefit the patient is inappropriate and should be terminated.

One of the conditions for life termination is that the doctor and the parents have collectively concluded that there is no other reasonable means of resolving the situation. However, in the debate surrounding neonatal life termination, relatively little attention has been given to alternative means of alleviating the suffering of neonates with very serious heath problems. Greater emphasis therefore needs to be placed on palliative sedation and on a more cautious approach to the commencement of life-prolonging treatment.

The Expert Committee's role involves reviewing not only neonatal life termination cases, but also abortions performed after the twenty-fourth week of pregnancy, if the foetus had a chance of survival. It is in principle a criminal offence to perform an abortion so late in a pregnancy. However, a doctor may justify such a procedure on the grounds of force majeure in the form of an emergency situation if a woman asks for a termination on the grounds that the baby she is carrying will be born with a serious medical condition. The State Secretary and Minister have indicated that the Committee may conclude that a doctor has acted with due care in such a case if: no doubt surrounded the diagnosis or prognosis, from which it was clear that the baby would be born with a condition whose postnatal treatment would be judged medically pointless; the foetus was experiencing hopeless acute suffering or would inevitably have faced hopeless suffering; the mother expressly requested termination of the pregnancy because of the physical or psychological burden placed on her by the situation; the doctor properly informed the parents about the diagnosis and prognosis and they collectively concluded that there was no other reasonable means of resolving the situation; the doctor consulted at least one other independent doctor or treatment team; and the abortion was performed with appropriate medical care.

In this context, 'acute suffering' implies the presence of foetal pain. Because many questions still exist regarding the perception of pain by foetuses and the feasibility of gauging the seriousness of such pain, additional research into this matter is desirable. The prospect of hopeless future suffering may be assessed by reference to the same focus points used to support

decisions regarding the provision of life-prolonging treatment to neonates and neonatal life termination. However, the uncertainties referred to in the latter context apply equally in this context. So, again, further standpoint definition and research are desirable.

1 Introduction

Congenital abnormalities, premature birth or perinatal complications can result in the birth of babies with very serious health problems. Those that have a chance of survival are often dependent on medical intervention, which may entail anything from enteral feeding to the support of vital functions and surgery. If it becomes apparent that, despite treatment, a neonate is liable to suffer greatly, be left with serious permanent disabilities, or face life in a vegetative state, doctors and parents can be confronted with a situation where it is arguably better to allow the child to die.

Deciding whether death is kinder is very difficult, not only for parents, but also for doctors. Medical practitioners have to decide whether starting or continuing treatment is beneficial or – in view of the suffering and handicaps that the neonate faces – in fact contrary to the patient's interests. Because doctors feel responsible for the lives of neonates whose (continued) existence depends upon their intervention, it can be very hard for them to know how best to proceed.[1,2]

In many cases where the death of a neonate with very serious health problems is acceptable or even desirable, mortality will result quickly from the withholding or withdrawal of treatment. Sometimes, however, there will be a delay, giving rise to an emergency situation. It may even prove that, contrary to expectations, a neonate is not actually dependent on treatment for its continued existence. In such cases, doctors and parents sometimes have to decide whether it is better to hasten the baby's end.

1.1 Expert Committee

Life termination is causing or hastening death by the administration of a substance intended to have that effect. Medically ending the life of a neonate is a criminal offence, which may constitute manslaughter (article 287 of the Penal Code) or murder (article 289 of the Penal Code), unless the doctor in question is able to justify his/her action on the grounds of force majeure in the form of an emergency situation.[3,4] A doctor who terminates a life must always report his/her action to the Coroner. The latter has to pass details on to the Public Prosecutor, who decides whether prosecution is in order.

Research performed by Van der Wal *et al* indicates that there are fifteen to twenty cases of neonatal life termination a year in the Netherlands.[5] However, only twenty-two cases were reported between January 1997 and June 2004.[6] The low reporting rate probably reflects doctors' misgivings concerning the judgement of life termination cases within the criminal system.* They doubt whether a criminal court judge will accept complex medical reasoning regarding the nature of appropriate care. As a result, they are unsure of what will be regarded as force majeure and what, therefore, may happen if they report a case.[7,8]

With a view to providing greater clarity in the review of neonatal life termination, the State Secretary for Health, Welfare and Sport and the Minister of Justice established an Expert Committee on 1 September 2006.[9] Since that date, a coroner has been obliged to report any case of life termination not only the Public Prosecutor, but also to the Committee. The Committee – which is chaired by a lawyer and additionally includes three doctors (who have a single collective vote) and an ethicist – has the task of reviewing life termination cases to determine whether the medical personnel involved exercised appropriate care. Its conclusions are subsequently communicated to the Public Prosecutor, who has to take them into account when deciding whether to make a prosecution. If the Committee concludes that the doctor has not exercised appropriate care, it is also required to inform the Health Care Inspectorate.[10,11]

The thinking behind the new procedure is that doctors are more likely to be open about their activities if life termination cases are reviewed by a Committee, which has greater insight into the dilemmas faced by medical practitioners than the Public Prosecutor or the criminal court, and which possesses the necessary knowledge of medical science and medical ethics. Greater openness on the part of practitioners promotes the transparency of the decision-making process and facilitates supervision and the promotion of good practice in this area.[8,12]

The State Secretary and Minister have indicated that the Expert Committee may conclude that due care was exercised in a life termination case if all the following conditions are met:

1 On the basis of medical knowledge, the neonate's suffering was deemed to be unbearable and hopeless. (This implies that the earlier decision to withhold or withdraw treatment was justified and that there was no doubt with regard to the diagnosis or related prognosis.)
2 The parents consented to the life termination.
3 The doctor properly informed the parents about the diagnosis and prognosis and they collectively concluded that there was no other reasonable means of resolving the situation.
4 The doctor consulted at least one other independent doctor or treatment team.
5 The life was terminated with appropriate medical care.[10,11]

With regard to definition of the terms 'hopeless' and 'unbearable', the State Secretary and Minister have sought to align their guidance with the Voluntary Euthanasia and Medically

* In section 4, it is suggested that the incidence of neonatal life termination may be higher than fifteen to twenty cases a year. If so, the reporting rate is even lower than indicated.

Assisted Suicide Act. 'Whether suffering may be deemed hopeless,' they write, 'should be judged on the basis of prevailing medical insights. Hopelessness implies the absence of any reason to believe that the patient's circumstances can ever be improved. The existence of intolerable suffering may be objectively determined, so the Advisory Committee should review the defensibility of the doctor's conclusion on a case-by-case basis.'[13]

1.2 Conflicting duties

A decision to terminate a life will always involve striking a balance between conflicting principles and must therefore be intrinsically problematic. Life termination arises out of a doctor's awareness of a duty to minimise and where possible prevent the suffering that a patient experiences as a result of an illness or disorder. In most cases, treatment will already have been halted, on the grounds that it is no longer beneficial, but the withdrawal of treatment will not have led swiftly to the death of the patient, who will therefore still face the prospect of serious suffering. However, in addition to the duty to alleviate and prevent suffering, the doctor has a duty to preserve the life of anyone entrusted to his/her care. This duty is of particular importance where the life of an incapacitated person is concerned, since such individuals cannot speak for themselves and are often completely dependent on others. In the case of a neonate, there is the additional consideration that such patients may ordinarily be expected to have a long life ahead.

The fact that a life is worth protecting implies that life-prolonging treatment is appropriate unless and until this is evidently not the case.[14] Only if it is clear that a neonate's life prospects are insufficient to outweigh the suffering faced, or if the only prospect is life in a vegetative state, can life termination be justified. In order to legitimately terminate the life of a neonate, a doctor must be able to demonstrate clearly that such a course of action is necessitated by his/her duty to alleviate and prevent suffering. Under such circumstances, the conflict between the latter duty and the duty to preserve life is deemed to constitute an emergency situation, the existence of which relieves the doctor of any criminal responsibility for his/her action. The assessment criteria the State Secretary for Health, Welfare and Sport and the Minister of Justice have laid down for use by the Expert Committee define the circumstances that characterise such an emergency situation.

The fact that a life is worth protecting also underpins the right to life, which is enshrined in, for example, article 2 of the European Convention for the Protection of Human Rights and Fundamental Freedoms. It is assumed that article 2 does not permit statutory provisions allowing the life of an incapacitated individual to be terminated under certain circumstances. However, the article in question is not believed to preclude the acceptance of a defence of *force majeure* made by a doctor who ends the life of a neonate. Nor should it preclude non-prosecution in cases where the prosecuting authorities have good reason to believe that a doctor can convincingly make such a defence. The acceptability of non-prosecution is not affected by the

decision of the prosecuting authorities being based upon the advice of the Expert Committee.[15-17]

1.3 Purpose and structure of this monitoring report

The point has been made by commentators at home and abroad that the Dutch guidelines on neonatal life termination are somewhat vague.[18,19] Accordingly, the Expert Committee now has the task of further developing and operationalising the assessment criteria. This is an important task, since the clearer the guidelines are, the more certain doctors can be in their decision-making, the greater the support there will be for the criteria and the more willing doctors will be to report their actions. This in turn will enhance supervision and promote the exercise of due care in this area. The underlying principle of Dutch policy on life termination is that it should ultimately improve the protection of life.

It is important that the Expert Committee is given the opportunity to further develop and operationalise the assessment criteria on the basis of casuistry. In this monitoring report, a number of general points pertinent to this process are addressed. Thus, the report identifies the unresolved ethical dilemmas and indicates the contribution that medical science can make to their resolution.

The report begins by describing the development of consensus on the regulation of neonatal life termination over the last fifteen years. This provides a context for discussion of the matters that still require clarification. The matters in question are: the acceptability of life termination outside the context of life-prolonging treatment, the nature of the clinical practice of life termination, the requirement that acute suffering should be present, the means by which a neonate's long-term health prospects may be assessed and alternatives to life termination. The examination of these matters in the context of neonatal life termination is followed by consideration of their parallels in the field of late abortion, in which the Expert Committee also acts as the responsible review body. The monitoring report concludes with a list of policy and research topics warranting attention.

1.4 Accountability

This monitoring report forms part of the Ethics and Health Monitoring Report 2007. It has been compiled under responsibility of the Standing Committee on Medical Ethics and Medical Law by the secretary, A Bood. The members of the Standing Committee are listed in Appendix 1.

2 Existing consensus

Over the last fifteen years, a degree of consensus has developed in the Netherlands regarding the circumstances under which neonatal life termination can be acceptable. The process began in the early 1990s, when doctors articulated their views on the matter in a series of reports produced by or in collaboration with representatives of the medical profession: *Doen of laten. Grenzen van het medisch handelen in de neonatologie* (*To do or not to do? Boundaries of Medical Action in Neonatology*), published by the Netherlands Association for Paediatric Medicine (NVK)[14], *Medisch handelen rond het levenseinde bij wilsonbekwame patiënten* (*Medical practices involving the end of life in incompetent patients*) published by the Royal Netherlands Society for the Advancement of Medicine's Committee on the Acceptability of Life-ending Treatment (CAL)[20] and *Toetsing als spiegel van de medische praktijk* (*Review as a reflection of medical practice*) published by the Consultative Group on the Review of Due Care in End-of-Life Medical Procedures Involving Neonates.[8] Some of the standpoints set out in these documents obtained a jurisprudential basis through the Prins and Kadijk cases.[3,4] The Public Prosecutor subsequently aligned its dismissal policy with the new case law.[6,13] The reports and jurisprudence also formed the basis for the *Protocol on Active Life Termination in Seriously Ill Newborns* ('Groningen Protocol'), which was adopted as a national guideline by the NVK in 2005.[21] Finally, the assessment criteria published by the State Secretary for Health, Welfare and Sport and the Minister of Justice for use by the Expert Committee drew partly upon the above-mentioned reports and jurisprudence.[10]

With a view to identifying the matters concerning which uncertainty still exists, this chapter begins by describing the existing consensus. Some views that prevail within the medical profession have yet to find any reflection in jurisprudence. Hence, the medical consensus is wider than the legal consensus.[22]

2.1 Withholding or withdrawing life-prolonging treatment

There is a fairly general consensus that neonatal life termination can sometimes be acceptable following a justifiable decision to withhold or withdraw life-prolonging treatment. This principle is embraced by the NVK and CAL reports, by the jurisprudence and by the assessment criteria issued to the Expert Committee. In practice, life termination is normally a corollary to a non-treatment decision. This is because when a child is born with very serious health problems, treatment is normally initiated immediately,[1,2] but it is often some days before a firm

diagnosis and prognosis can be made. Hence, the criteria for assessing the acceptability of life termination can best be considered against the background of the guidelines governing non-treatment decisions.

Legally speaking, withholding or withdrawing treatment is in principle 'normal medical practice'. Such practice may consist of action that potentially supports medical objectives, or the cessation of action that can no longer be regarded as beneficial. Within certain general boundaries, such as those defined in the Medical Treatment Contracts Act, the medical profession itself regulates normal medical practice by issuing professional guidelines and protocols. On the basis of the 'medical exception', normal medical practice cannot be criminal, even if its effect is to shorten life.

Withholding or withdrawing treatment is deemed to be normal medical practice if the treatment is 'medically futile'. A treatment is such if:

a it does not contribute to maintenance or improvement of the patient's medical condition; or
b the means of treatment are disproportionate to the realisable objective; or
c a particular minimum level of health can no longer be attained.[15,23]

In principle, it is up to the doctor to decide whether treatment is medically futile. On the basis of the guidance issued by the NVK and CAL, it may be assumed that the non-treatment of a neonate is justified under two circumstances: if treatment has no prospect of success, insofar as there is no chance of survival; or if it is 'futile', insofar as the neonate's prognosis offers no prospect of a reasonable quality of life. Since a neonate with no prospect of a reasonable quality of life will typically also have a poor chance of survival, there is in practice often little to distinguish these circumstances from each other.[7]

Treatment may be deemed to have no prospect of success in cases of, for example, anencephaly, Potter's syndrome, triploidy, trisomy-13 and trisomy-18. These conditions bring either no chance of survival or the prospect of survival for no more than a year. The non-treatment of a neonate with such a condition is not normally therefore controversial.

Controversy can arise, however, in cases where treatment is deemed futile. A conclusion that treatment offers no prospect of a reasonable quality of life is necessarily based upon a prediction regarding the likelihood of serious disability arising. The implications of a disability for the subjective quality of a neonate's future life cannot be determined on a purely factual basis; inevitably a value judgement has to be made.

There is a fairly general consensus that a doctor may make such a value judgement, provided that he or she does so within a medical reference framework. The NVK and CAL reports identify the following considerations as relevant to such a judgement: the anticipated ability to communicate and form relationships; the anticipated degree of suffering; the anticipated

degree of self-sufficiency (including dependency on medical assistance); the anticipated development capability; and the life expectancy. According to the CAL, it is possible to assess a neonate's quality-of-life prospects with a reasonable degree of confidence, since the likelihood of certain conditions seriously diminishing the of quality of life perceived by the sufferer is sufficiently great as to border on probability.[14,20,24]

This approach to the justification of non-treatment decisions was endorsed by Amsterdam High Court in the Prins case and by Leeuwarden High Court in the Kadijk case.[3,4] The relevant principles also partly underpin the assessment criteria issued to the Expert Committee. According to the State Secretary for Health, Welfare and Sport and the Minister of Justice, a decision to withhold or withdraw treatment may be deemed normal medical practice if the patient has no chance of survival or no prospect of acceptable health in the future. Assessment of a neonate's health prospects may be based upon the anticipated degree of suffering, life expectancy, seriousness of the available treatments, anticipated ability to communicate, anticipated self-sufficiency and degree of dependency on medical assistance.[10]

2.2 Life termination

Life termination is more controversial than shortening life by non-treatment. The administration of a substance with the aim of hastening death is never normal medical practice. Voluntary euthanasia performed by a doctor in accordance with the requirements of the Voluntary Euthanasia and Medically Assisted Suicide Act is not a criminal offence (article 293 of the Penal Code). However, life termination that the patient has not requested is a criminal offence – either manslaughter (article 287 of the Penal Code) or murder (article of the 289 Penal Code). In principle, this is the case with the medically induced death of a neonate.

Nevertheless, most doctors believe that it is sometimes incumbent upon them to end the life of a neonate. The report *Doen of laten?* identifies two circumstances in which life termination can be justified. First, a situation in which life-prolonging treatment is withheld or ended because a neonate's quality-of-life prospects are so poor, but death does not swiftly follow, giving rise to an emergency situation entailing suffering that cannot responsibly be allowed to continue. Second, a situation in which a neonate faces an 'intolerable quality of life' having been kept alive by a medical intervention, which was performed at a time when the prospects for the neonate remained unclear, and would not have been justified if those prospects had been clear. Under the latter circumstances, the report indicates that a doctor has a special responsibility to curtail treatment. However, if the neonate is no longer dependent on the treatment for survival, curtailment will not lead to death. The report suggests that most doctors will then feel a responsibility for the consequences of the earlier intervention, sufficient to make them regard life termination as acceptable.*

* In this context, earlier medical intervention may include intervention begun before birth, such as the inhibition of contractions, the administration of medication to the mother to promote foetal lung maturation, or the performance of a Caesarean section, e.g. due to a foetal emergency.

According to the NVK, consensus is not universal regarding the acceptability of life termination under the circumstances described above, but the minority of doctors who do not regard it as acceptable are able to respect the majority view.[14] The CAL report also draws attention to the fact that not all medical practitioners support the approach advocated in *Doen of laten?* but the CAL has nevertheless apparently given its backing to that approach. Furthermore, the CAL takes the view that, if the death of a neonate is expected to follow within hours or days of treatment being withheld or withdrawn, life termination may be regarded as appropriate palliative care.[20]

In the Prins and Kadijk cases, the courts accepted the principle that life termination can be defensible following a justifiable non-treatment decision. A doctor who ends the life of a neonate following such a decision may under certain circumstances claim to have acted under *force majeure* in the form of an emergency situation.

The Prins case involved a situation such as that described in *Doen of laten?* where non-provision of life-prolonging treatment did not swiftly lead to the patient's death, giving rise to an emergency situation entailing suffering that cannot responsibly be allowed to continue. The patient was a neonate with a very serious form of spina bifida and acute pain. The prognosis was very poor (disabilities that would cause serious suffering, permanent dependency on medical assistance, risk of prolonged subcoma with respiratory problems as a result of the need for pain killers). In view of these factors, the court regarded Prins' decision to not perform a surgical procedure that could have prolonged the life of the neonate as consistent with the consensus within the medical profession. The court also accepted the view of expert witnesses that controlling the baby's acute pain was medically futile. As a result of the decision not to operate, the patient's life expectancy was just a few months. The neonate's pain could have been suppressed, but that would have increased the risk of complications and led to an extremely distressing situation for the parents and the doctors involved in the case. There was consequently no good alternative to life termination and Prins was justified in concluding that his duty to end the patient's suffering outweighed his duty to preserve the baby's life. Because the parents had also given their consent for the life termination, Prins was judged to have acted with due care and not to have committed a criminal offence.[3]

The Leeuwarden High Court adopted a similar line of reasoning in the Kadijk case, which combined elements of both the situations described by the NVK. The neonate had been kept alive by ventilation at a time when its quality-of-life prospects were unclear, but its continued existence no longer depended on treatment. Nevertheless, an emergency situation existed, insofar as the patient was suffering acutely. In this case, the patient was a neonate with trisomy-13, a chromosomal abnormality that gives rise to serious functional disorders and a greatly reduced life expectancy. The baby probably had just a few months to live, at most. Shortly after birth, the baby developed serious complications, causing considerable pain. The court accepted the view of expert witnesses that Kadijk had rightly decided to withhold ventilation, reanimation and surgery, on the grounds that they would be disproportionate. Referring

to the NVK report and an earlier discussion document published by the CAL,[25] the court ruled that Kadijk's decision not to wait until the patient died naturally, but to grant the parents' life termination request, was justified. Thus, Kadijk was also judged not to have committed a criminal offence.[4] *

In all twenty-two cases of neonatal life termination recorded in the period January 1997 to June 2004, the Public Prosecutor decided not to prosecute, on the grounds that it was anticipated that the doctor could legitimately claim to have acted under *force majeure*, since all the conditions identified by the Amsterdam and Leeuwarden High Courts had been satisfied.[13] All the cases involved neonates with a primary diagnosis of spina bifida. Notably, the Public Prosecutor did not independently seek to establish whether the babies concerned were suffering hopelessly. The doctors' assertion that such suffering existed was accepted.[6]

According to the assessment criteria drawn up by the State Secretary for Health, Welfare and Sport and the Minister of Justice for use by the Expert Committee, life termination may be acceptable where there is 'hopeless and unbearable suffering'. Life termination is then countenanced in two situations. First, where it is known that the neonate will shortly die, and the baby's death is deliberately hastened in order to prevent it suffering. In defining this situation, the State Secretary and Minister appear to have had in mind cases such as the Kadijk case, where life termination follows the withholding or withdrawal of treatment that has no prospect of success.

The second situation identified by the State Secretary and Minister is one in which 'the neonate could be kept alive, but has no prospect of better health and therefore faces constant unbearable and hopeless suffering and has no chance of leading an independent life.'[10] In such a situation, life termination is consistent with the Prins ruling and with the criteria for the acceptability of life termination described in *Doen of laten?* namely the existence of an emergency situation involving suffering that cannot responsibly be allowed to continue, following the withholding or withdrawal of life-prolonging treatment on the grounds that the patient faced an unacceptably poor future quality of life.

* The Leeuwarden High Court noted that, following the non-treatment decision, Kadijk had a choice between pain management and life termination. However, unlike its counterpart in Amsterdam, the Leeuwarden High Court did not explicitly identify the medical futility of pain management as a condition for the acceptability of life termination; the validity of Kadijk's conclusion that such treatment was indeed futile was not therefore examined. Possibly the court considered the futility of pain management to be evident, in view of the complications described and the conclusion drawn by the other doctor consulted by Kadijk, namely 'that further erosion of hope and aggravation of the patient's suffering were likely to follow.'

3 Life termination outside the context of life-prolonging treatment

As indicated above, *Doen of laten?* reports that life termination is acceptable to a majority of paediatricians in two situations. First, where life-prolonging treatment has been withheld or withdrawn on account of the patient's poor quality-of-life prospects, but death does not swiftly follow, thus giving rise to an emergency situation entailing suffering that cannot responsibly be allowed to continue. Second, where a neonate faces an intolerable quality of life, having previously been kept alive by medical intervention at a time when the quality-of-life prospects remained unclear. Under the latter circumstances, the report indicates that life termination is acceptable on the grounds of the doctor's responsibility for the consequences of the earlier intervention.

However, neonatal life termination may be considered outside the context of life-prolonging treatment and its non-provision. Of relevance here are cases where a neonate's continued existence neither depends nor has previously depended on medical treatment; although with normal care the neonate can survive ('remain stable') for a longer period, it has very serious health problems and its long-term prospects are bleak. The extent to which a consensus exists regarding the acceptability of life termination under such circumstances is not clear. Furthermore, a situation such as that described in this paragraph is not necessarily readily discernible from those described earlier, since it is not always apparent whether a neonate is dependent on a given treatment for survival.

3.1 Groningen Protocol

At the time that *Doen of laten?* was written, there was no consensus regarding the acceptability of life termination outside the context of life-prolonging treatment. According to the report, there is no real medical dilemma outside the latter context: 'medically and morally speaking, a dangerous situation [is liable to arise], if deliberate life termination becomes generally acceptable other than in emergency situations (involving life-prolonging medical intervention).'[14]

However, the more recent *Protocol on Active Life Termination in Seriously Ill Newborns* ('Groningen Protocol') is based upon a different standpoint. The Groningen Protocol distinguishes three circumstances under which life termination may be considered:

a A situation where the neonate's death is imminent, despite intensive treatment
b A situation where intensive treatment may enable the neonate to survive, but with bleak quality-of-life prospects
c A situation where the neonate is not/no longer dependent on intensive treatment for survival, but faces a life of serious and hopeless suffering.*

The protocol assumes that, in the first two circumstances, the consideration of life termination constitutes normal medical practice. Hence, the protocol concerns itself with neonatal life termination in situations of the third kind, involving neonates with abnormalities so serious as to preclude any form of independent existence and to imply constant serious suffering that cannot be alleviated. The authors suggest that this might include those with very extensive forms of spina bifida and the most serious form of the skin disease epidermolysis bullosa. The report of the Consultative Group on the Review of Due Care in End-of-Life Medical Procedures Involving Neonates suggests lissencephaly (a serious congenital brain disorder) as another example of a condition that might give rise to such a situation.[8]

Because such neonates are not or are no longer receiving intensive life-prolonging treatment, it is not possible to end their suffering by the withdrawal of treatment. According to the protocol, a doctor may under such circumstances decide to monitor the patient until the child's suffering comes to an end. Given that the neonate is not or no longer dependent on intensive treatment of its condition for survival, the protocol's authors presumably envisage an end brought about by death from a complication such as meningitis. They go on to say that waiting for nature to take its course in this way is unacceptable to most doctors. Thus, a conflict arises between the doctor's duty to preserve life and the duty to alleviate suffering. The protocol describes how a doctor should proceed if the latter duty is felt to outweigh the former. Guidance is given in connection with diagnosis and prognosis, consultation with the parents and the submission of a report to the coroner.[21,27,28]

The protocol countenances life termination under circumstances regarding which *Doen of laten?* suggested that no general consensus existed, i.e. in cases where the neonate may never have been dependent on intensive treatment. By referring to intensive life-prolonging treatment, the protocol does not depart from the line taken in *Doen of laten?* with regard to neonates who are dependent only on basic medical care, such as artificial nutrition, for survival. According to *Doen of laten?* life termination is acceptable for such neonates only if the care is medically futile and its withdrawal creates an emergency.** Nor does the protocol depart from the NVK report in relation to neonates that have previously been dependent upon such care. What distinguishes the protocol is that it does not rule out life termination in a situ-

* The distinction between the three groups is based on the recommendations of a working group of the Confederation of European Specialists in Paediatrics,[26] which were not concerned with life termination.

** *Doen of laten?* recognises various forms of care, other than palliative care: normal care (as provided by parents), basic medical care (incubator care, enteral feeding, medication, etc), intensive care (care that supports or takes control of the vital functions) and surgical care. According to the report, the latter three types of care may be regarded as life-prolonging treatment (although the point is made that some paediatricians regard enteral feeding as a fundamental form of care, whose withdrawal is not an option).

ation where a neonate is not dependent and has never been dependent either on intensive treatment or on basic medical treatment.

3.2 Responsibility for a neonate's subsequent life

It is important to evaluate this extension of the circumstances under which life termination may be considered acceptable. It may reasonably be argued that the first and second situations envisaged in *Doen of laten?* differ from one another more fundamentally than the second differs from the Groningen Protocol's additional situation. The reason being that, in the first situation, life-prolonging treatment is futile, its non-provision is therefore the obvious course of action and the infant's death an inevitable consequence of that action. Thus, life termination merely influences the timing of death. The second situation is quite distinct from the first insofar as the neonate's existence no longer depends on the provision of treatment. In this second situation, the justification for life termination is based not on the patient's actual circumstances (following the withholding or withdrawal of treatment), but on the grim prospects associated with the patient's very serious health problems. In other words, what is at issue is not merely the timing of the neonate's death, but *whether* the neonate should die.

The additional situation countenanced by the Groningen Protocol shares this distinction from the first *Doen of laten?* situation. However, it also differs from the second *Doen of laten?* situation insofar as it does not involve action as a corollary to the life-prolonging treatment process, for whose consequences the doctor bears a responsibility according to the report. The protocol is based upon the premise that a doctor also has a responsibility for the neonate's subsequent life even if no life-prolonging treatment has been provided. This responsibility derives from the doctor's duty to act in the neonate's interests and from the doctor's power to end the neonate's life if it is characterised by serious and hopeless suffering.

If one accepts that a doctor has a responsibility for a neonate's subsequent life, this diminishes the significance of the argument presented in *Doen of laten?* that life termination can be acceptable on the grounds that a doctor is responsible for the consequences of earlier life-prolonging treatment. Hence, the protocol places neonates that are no longer dependent on intensive treatment for survival in the same group as those that have never been thus dependent. Thus, the question of responsibility for earlier life-prolonging treatment ceases to be relevant. Indeed, it is not addressed by the CAL's final report.* Furthermore, this question does not appear to have played any part in court rulings in this field. For the scope of the Kadijk case ruling, for example, what mattered was not that Kadijk's action was motivated by the poor quality of later life faced by the neonate (as in the two situations envisaged by *Doen of laten?*), but that treatment had no prospect of success because of the patient's trisomy-13. Thus, there

* It was addressed, however, in the CAL's 1990 discussion document.[25] In the 1990s, the argument was criticised mainly on legal grounds. See, for example, Leenen 2000: 'The fact that an action has had undesirable consequences does not in itself legitimise otherwise unacceptable corrective action.[15] Such criticism may explain why the relevant passage of the discussion document was not included in the final report.

is no jurisprudential support for life termination intended to spare a neonate an intolerable later life and justified by a doctor's responsibility for earlier life-prolonging treatment.

3.3 Consensus?

Opinion differs as to whether a doctor may be considered responsible for a neonate's subsequent life if life-prolonging treatment has not previously been given. It is therefore debatable to what extent life termination outside the context of life-prolonging treatment – for which justification is claimed on the basis of that responsibility – is in fact considered acceptable outside NVK circles.

The CAL report does not address the issue of life termination outside the context of life-prolonging treatment. Only life termination following the withholding or withdrawal of such treatment is explicitly discussed. Nor does jurisprudence yet afford any support for life termination outside the context of life-prolonging treatment, since no case involving such life termination has so far been brought to court. As indicated earlier, the Prins case involved an emergency situation entailing suffering that could not responsibly be allowed to continue, following a decision not to provide life-prolonging treatment. The Kadijk case concerned an emergency in which the patient – a neonate with an untreatable condition – was suffering acutely, having previously been kept alive by a ventilator, before the child's quality-of-life prospects were known.

It is not clear whether the State Secretary for Health, Welfare and Sport and the Minister of Justice consider life termination outside the context of life-prolonging treatment to be acceptable. In the first of the two situations they describe in the notes accompanying the assessment criteria drawn up for the Expert Committee, in which life termination is justified by the patient's 'unbearable and hopeless suffering', the neonate's death is already imminent and merely hastened in light of the seriousness of its suffering. In the second situation 'the neonate could be kept alive, but has no prospect of better health and therefore faces constant unbearable and hopeless suffering and has no chance of leading an independent life.' Perhaps the State Secretary and Minister take the view that, in situations of the second type, life termination may be considered only if the neonate is dependent on treatment for its continued existence and if life-prolonging treatment has been withdrawn. However, if no such restriction was intended, it is unclear whether life termination involving a neonate that is not dependent on treatment for its continued existence can be acceptable only if the neonate has previously been kept alive by medical intervention before its quality-of-life prospects were known (as suggested in *Doen of laten?*), or whether it can also be acceptable outside the context of life-prolonging treatment (as in the additional situation described by the Groningen Protocol).*

In other words, the clear consensus that exists regarding life termination in an emergency situation following a justifiable non-treatment decision is not mirrored where life termination outside the context of life-prolonging treatment is concerned. However, in the light of recent developments, particularly in the field of diagnostics, it is increasingly apparent that 'real medical dilemmas' concerning life termination can also arise outside the context of life-prolonging treatment. Indeed, this recognition was one of the drivers for development of the Groningen Protocol. Hence, there is a need for further standpoint definition and for the medical profession to look again at *Doen of laten?* and the CAL's final report with a view to providing greater clarity regarding the basis for and boundaries of acceptable life termination.*

* It should be noted that a non-treatment decision and a decision to proceed with life termination are sometimes taken together. This is liable to be the case, for example, where treatment is not necessary to sustain life, but is provided with a view to improving or stabilising the health of the neonate, who nevertheless experiences serious and hopeless suffering. Under such circumstances, withholding or withdrawing treatment is reasonable only if a doctor simultaneously decides to proceed with life termination, since otherwise the non-treatment decision will lead to increased suffering through a deterioration in the neonate's health. The State Secretary and Minister appear to assume that a decision to terminate a newborn's life is always preceded by a non-treatment decision; their first assessment criterion, for example, requires that the non-treatment decision is justified.[10]

* The NVK Committee on Paediatricians, Ethics and Law is presently preparing a discussion document describing the views held by paediatricians regarding hopeless and intolerable suffering in neonates.

4 Clinical practice

Internationally, little research has been conducted into the practice of neonatal life termination. One exception to this general picture is the EURONIC survey of neonatologists in seven European countries (Germany, France, Italy, the Netherlands, Spain, the UK and Sweden). The majority of doctors surveyed reported having at one time or another taken a decision with potentially life-shortening implications. However, only in France and the Netherlands had a significant proportion of doctors ever administered a substance to a neonate with the intention of shortening its life (the respective figures being 73 per cent and 47 per cent, compared with 2 to 4 per cent in the other five countries). However, it is questionable whether the differences between the various countries are actually as great as the survey indicated. The researchers themselves make the point that there is often a degree of ambiguity in a doctor's intentions, such that it can be hard to distinguish between life termination and the intensification of pain and symptom management with a potentially life-shortening effect. The majority of doctors (64-89 per cent) in all countries except Italy had experience of situations of the latter type.[29]

The Netherlands is one of the few countries where it is possible to approximate the incidence of neonatal life termination and indicate the circumstances under which it occurs. Nevertheless, we do not have a full picture of what takes place in the Netherlands. As indicated earlier, difficulties surrounding the recording of doctors' intentions complicate the registration of life termination practices, even in our country.[12,30] Furthermore, the picture tends to be obscured by differences in interpretation of the term 'life termination' and by a paucity of information concerning the variables that characterise cases in which a substance is administered with the express intention of hastening death, such as the health status of the neonate, the factors considered by the doctor and (where relevant) the nature, dosage and duration of the medication administered.

4.1 Evaluation studies

The data concerning neonatal life termination practices in the Netherlands come from evaluation studies into the practice review of euthanasia published by Van der Wal *et al* in 1995 and 2001.[5,31,32] The study findings indicated that 45 per cent of the surveyed paediatricians working in a neonatological or paediatric intensive care unit had at some time ended the life of a neonate; 29 per cent had not done so, but said they would consider doing so under appropriate circumstances.[7 *]

In 68 per cent of the 1008 fatalities involving infants under the age of twelve months in 2001, death was preceded by a medical decision that had a bearing on the child's death. In 73 per cent of such cases, the neonate was judged to have no real change of survival; while in 24 per cent of cases, the likelihood of a tolerable life was rated very small or non-existent.

In 63 per cent of the cases in which a medical decision was taken that had a bearing on the child's death, the decision entailed withholding or withdrawing a potentially life-prolonging treatment. In 14 per cent of cases, the decision was made knowing that it would probably or certainly hasten the patient's death. In the other 49 per cent of cases, the decision was made with the express intention of hasting death. A non-treatment decision was followed by the intensification of pain or symptom management in a manner liable to have a life-shortening effect in 29 per cent of all mortality cases. In 8 per cent of cases, the non-treatment decision was followed by the administration of a substance with the express aim of hastening death.

In 3 per cent of all mortality cases, pain or symptom management was intensified in a manner liable to have a life-shortening effect, in isolation from any non-treatment decision. In 1 per cent of cases, a substance was administered with the express aim of hastening death, in isolation from any non-treatment decision.

The report on the 1995 study looked in more detail at the diagnoses that were liable to lead to life termination. It was found that 80 per cent of cases involved a neonate with a congenital abnormality: 35 per cent of the infants had abnormalities of the central nervous system, 29 per cent had multiple congenital abnormalities, 8 per cent had congenital heart abnormalities and 8 per cent had other congenital abnormalities. In 16 per cent of the life termination cases, oxygen deprivation during birth was the cause of the neonate's very serious health problems. The estimated period by which life was shortened by the administration of a substance was less than a week in 40 per cent of the cases. In 23 per cent of cases, the period was put at more than a week but less than a month, in 3 per cent at one to six months and in the remaining 16 per cent at more than five years. No such estimate was possible in 18 per cent of cases.[7]

4.2 Life termination?

According to Van der Wal *et al*, a substance was administered with the express aim of hastening death in 9 per cent of all the mortality cases studied, either in connection with or outside the context of a non-treatment decision. The number of neonates thus affected was approximately a hundred in 2001. However, the researchers classed a death as life termination only if not preceded by a non-treatment decision. Hence, they arrive at a figure of fifteen to twenty deaths in 2001.

* Compare Vrakking *et al* 2005: agreement with the proposition that life termination can be acceptable if parents believe that their baby is suffering intolerably was greater among paediatricians (68 per cent) than among other specialists (43 per cent) or GPs (45 per cent). The authors suggest that the difference may reflect paediatricians' greater experience of discussing important medical decisions with parents.[33]

The other eighty to eighty-five cases, in which a substance was administered in connection with a non-treatment decision with the express aim of hastening death, were not regarded as life termination cases by Van der Wal *et al*. Their reasoning was that, in such cases, the neonate was expected to die, regardless of the administration of a life-shortening substance, as a result of life-supporting treatment being withheld or withdrawn. However, this line of reasoning is not universally accepted.

The line taken by Van der Wal *et al* is consistent with the view held by many doctors that, if death is inevitable within a matter of days or hours, the administration of a life-shortening substance constitutes palliative care, rather than life termination. This school of thought contends that, under such circumstances, death is not caused by the doctor, but merely accelerated in order that it is not unnecessarily protracted. This view was supported by the authors of both *Doen of laten?* and the Groningen Protocol, amongst others.

Legally, however, the administration of a substance with the aim of hastening death is life termination even under such circumstances, and should accordingly be reported as such.* A medically induced death is not life termination only if the substance that brings it about is medically indicated, e.g. for the professionally justifiable management of pain. The administration of a life-shortening substance under such circumstances constitutes normal medical practice. On the basis of the 'medical exception', normal medical practice cannot be criminal, even if its effect is to shorten life and regardless of the doctor's intentions.[12] Nevertheless, as indicated by the CAL, the Consultative Group on the Review of Due Care in End-of-Life Medical Procedures Involving Neonates and others, the obligation to report a death exists regardless of whether the deceased was expected to die shortly as a result of a non-treatment decision.[8,20] Even in cases where death is imminent, the reporting of such deaths is desirable for reasons of transparency.

Of the eighty to eighty-five cases involving the administration of a substance with the express aim of hastening death following a non-treatment decision, it is not known how often the relevant course of action was chosen on medically justifiable grounds. The possibility cannot be excluded that, in some cases, a substance was administered to, for example, ensure that the parents of the neonate were able to be with the infant when it died.[2] It therefore appears that in 2001 there were more than fifteen to twenty cases of life termination in the Netherlands that should have been reported.

It should be recognised that life termination as defined in law may take various forms. However, because little is known about the eighty to eighty-five cases referred to above, it is difficult to classify them in medical or ethical viewpoint. It may be that some of the cases did not involve what doctors regard as palliative care (when death is imminent), but situations of the kind envisaged in *Doen of laten?* where life-prolonging treatment was withheld or withdrawn,

* In line with established criminal law standards, an act may be deemed deliberate if the doctor accepts the probability that death will occur; the act need not have been performed with the express intention of shortening life.[12]

but death did not follow swiftly, thus giving rise to an emergency situation involving suffering that could not responsibly be allowed to continue.

One practical difficulty that exists is that it is not always clear whether a patient is dependent on a treatment for survival. In medical circles, therefore, there is liable to be disagreement as to whether the neonates involved in the eighty to eighty-five cases would indeed have died as a result of treatment being withheld or withdrawn. This point was illustrated by a US survey of 159 paediatricians, which found that such specialists were liable to underestimate premature neonates' survival chances and chances of growing up without serious disability. Among neonates born after less than twenty-seven weeks' gestation, the actual chance of survival was more than twice what paediatricians' prognoses suggested. The pattern was maintained for premature babies born before the thirty-fifth week. Doctors who took a more pessimistic view of neonates' chances were more likely to decide against intensive treatment than doctors who took a more optimistic (and, it proved, a more realistic) view.[34] In the Netherlands, a study in which five gynaecologists were asked to review a hundred case histories, four came to the same conclusion about the viability of a foetus with multiple abnormalities in just 67 per cent of the cases.[35] *

If the assumption that the neonate would have died as a result of treatment being withheld or withdrawn was in fact unjustified in some cases, then some of the eighty to eighty-five cases should have been classified as life termination, even under the definition applied by Van der Wal *et al*.[8,36]

4.3 Baseline data

In autumn 2006, a new study of neonatal life termination practices was started. The intention is to provide baseline data that can be used to study the effect that introduction of the Expert Committee system has on doctors' inclination to report cases of life termination.[13] In view of the uncertainties outlined above, it is appropriate to interpret the term 'life termination' in its legal sense for the purposes of the study and to review the details of the eighty to eighty-five cases not treated as life termination by Van der Wal. Of relevance in the latter context are the health status of the neonate, the factors considered by the doctor and (where relevant) the nature, dosage and duration of the medication administered.

Such case details are also needed in order to establish how often life termination occurs in situations of the kind envisaged by the Groningen Protocol, i.e. where a neonate is not (any longer) dependent on intensive treatment for survival, but nevertheless faces a life of serious and hopeless suffering. That is not presently apparent, regardless of the uncertainties referred to above. According to the authors of the protocol, all the cases classified as life termination by Van der Wal *et al* involved situations of the kind described.[28] However, such cases may

* One of the five gynaecologists was unable to make a judgement in twenty-four cases, asserting that there was insufficient information, the diagnosis was unclear, no prognosis could be made or a combination of these factors applied.

involve either a neonate that has no realistic chance of survival, or one who is expected to survive, but with an intolerable quality of life. Yet only neonates of the latter kind should be included in the group referred to. As indicated above, in 73 per cent of cases involving a medical decision that has a bearing on the end of a neonate's life, the infant is considered to have no realistic chance of survival, while in 24 per cent of cases, the infant is expected to survive, but with a negligible chance (if any) of a tolerable life.

5 Acute suffering

According to the assessment criteria drawn up by the State Secretary for Health, Welfare and Sport and the Minister of Justice for use by the Expert Committee, life termination can be acceptable only in cases where a neonate is experiencing 'hopeless and unbearable suffering'. Such suffering may occur in two types of situation. First, where it is clear that the neonate will die before long, and the degree of suffering is felt to justify deliberately expediting the inevitable. Second, where the neonate could be kept alive, but there is no prospect of any improvement in the child's health sufficient to enable it to lead an independent life.

However, the State Secretary and Minister also indicate in their covering letter that a decision to terminate a life may be based only on acute suffering, i.e. suffering that the infant is already experiencing.[10] This suggests that acute suffering is a precondition for life termination, even in the second situation. This would be in line with the State Secretary's and Minister's wish for consistency with the terminology of the Voluntary Euthanasia and Medically Assisted Suicide Act; 'unbearable and hopeless suffering' in the sense of the latter act is interpreted as meaning acute suffering in all cases. However, because no further reference is made to this matter in their letter, it is not certain whether the State Secretary and Minister intended the acute suffering condition to apply in relation to all cases of neonatal life termination. The existence of doubt concerning this point is liable to deter doctors from reporting life termination cases.

5.1 Arguments for and against

At first sight, it would seem natural that the regulation of life termination should be based on the acute suffering criterion, since the presence of such suffering is the principal cause of medical emergencies that must be addressed. This point was made, for example, in the debate surrounding the twenty-two cases of life termination reported by doctors between January 1997 and June 2004, which did not lead to prosecutions. Some doctors take the view that neonates with spina bifida experience little or no pain or other forms of acute suffering and that any pain that they do experience can be effectively alleviated by straightforward means. Hence, it is argued, the presence of spina bifida can never justify life termination.[37-40]

However, arguments can be put forward for not insisting on acute suffering in all cases. It is a doctor's duty not only to alleviate the suffering associated with the patient's illness or disorder, but also, where possible, to prevent it. A situation could arise, where a neonate faces the pros-

pect of such serious suffering, that the doctor believes that his/her duty to prevent that suffering outweighs his/her duty to preserve the infant's life. Under such circumstances, the doctor may consider it irresponsible to defer life termination until such time as the suffering becomes hopeless and unbearable. Doctors are often acutely aware of their responsibility to prevent such suffering. Hence, *Doen of laten?* indicates that life termination can be acceptable if a neonate faces a future characterised by an intolerable quality of life. The Groningen Protocol is based on a similar assumption.

Another argument against making acute suffering an absolute precondition for neonatal life termination is that it is not a precondition for withholding or withdrawing treatment. If it is a precondition for life termination, doctors are liable to be cautious about initiating life-prolonging treatment. In practice, when a child is born with very serious health problems, treatment is normally initiated before a firm prognosis can be made. A situation can then arise where, by the time it becomes apparent that the prospects are bleak, the infant is no longer dependent on treatment for survival. Thus, having initiated treatment merely in order to give the neonate a chance, the doctor may find that he/she no longer has the option of allowing the child to die by withdrawing treatment. However, if life termination is acceptable only on condition of acute suffering, and if the infant's suffering has yet to become unbearable, the doctor will not be able to prevent future serious suffering by life termination. Research has shown that doctors sometimes seek to avoid such situations by withholding (further) life-prolonging treatment in the early stages of a neonate's life, so that they do not subsequently find themselves responsible for having kept the infant alive inappropriately.[1,2] Whether it is desirable for doctors to behave in this way is open to question.

5.2 Further standpoint definition desirable

In view of the foregoing, clarification regarding the applicability of the acute suffering requirement is desirable. Reconsideration of this matter may lead to the conclusion that neonatal life termination need not be regulated on the same basis as voluntary adult euthanasia.

In this context, it would be helpful to define what constitutes acute suffering and how its presence may be determined. Scientific understanding of the perception of pain by neonates is currently sketchy, and instruments for measuring neonatal pain remain under development. Furthermore, the application of an acute suffering requirement implies that life termination is acceptable only if all proportionate means of alleviating suffering have been attempted without success. Also, little is known about the side-effects of giving painkillers to very young children. Further research is required to address these problems.[41-43] *

* Research into the pain experienced by neonates with spina bifida is currently being conducted in Rotterdam.[18]

6 Grave long-term health prognosis

According to the State Secretary and Minister, ‘unbearable and hopeless suffering’ may sometimes be deemed present under circumstances where a neonate could be kept alive. This may be the case if there is no prospect of any improvement in the child’s health sufficient to enable it to lead an independent life. It is not clear what this ‘grave long-term health prognosis criterion’ implies, or how a doctor may legitimately determine that such a prognosis exists.

6.1 Quality of life

In the past, a grave long-term health prognosis has been referred to as the prospect of an intolerable quality of life.[14,25] However, in its final report, the CAL argued that the latter phrase was too apodictic, and it has subsequently been superseded by more neutral wording.20 However, what is referred to is not a neonate’s medical prognosis, but the implications of the prognosis for the child’s quality of life, as he or she perceives it. For this reason, *Doen of laten?* emphasises that, once a medical prognosis has been made, two further steps are required before the long-term health prognosis for a neonate may be considered grave. First, the likelihood of serious disability must be extrapolated from the medical data. Second, the ability of the child and its family to cope with the suffering associated with the disability must be assessed.[14]

As indicated above, the NVK and CAL reports identify a number of points (subsequently largely adopted by the State Secretary and Minister) that should be considered when implementing these two further steps. The points in question are the anticipated degree of suffering, life expectancy, the seriousness of the available treatments, the anticipated ability to communicate, the anticipated degree of self-sufficiency and the anticipated degree of dependency on medical assistance. From this list, it is clear that the concept of serious suffering is not limited to physical suffering (pain, breathing difficulties, discomfort), but also embraces psychosocial problems (such as the undermining of hope by the need for repeated surgery).

In other countries, there has been debate regarding the admissibility of future quality of life as a factor in a decision with a bearing on the ending of a neonate’s life. In the Netherlands and elsewhere, there has been a growing recognition that, if one rejects the notion that life must be prolonged as far as possible, one is obliged to make assessments of patients’ future quality of

life.[20,44-47] However, the basis on which such an assessment should be made is not yet entirely clear.

6.2 Differences of opinion

According to the CAL, the likelihood of certain conditions seriously diminishing the quality of life perceived by the sufferer is sufficiently great as to border on probability.[20] However, recent debate regarding the prognosis for neonates with spina bifida has demonstrated that there is as yet no general consensus among doctors regarding assessment on the basis of the five key points. Researchers have found, for example, that the quality of life for adults with spina bifida is no worse than that experienced by people with other serious physical disabilities.[18,48-50] It has also been argued that the level of independence and intelligence attainable by a person with spina bifida or hydrocephalus cannot be predicted in infancy with any reasonable degree of confidence.[37,48,51]

Support for these views can be found in published research findings. For example, a Scandinavian study of 486 spina bifida cases found that, in half the cases, there was a discrepancy between the medical prognosis made in the patient's infancy and the disability described by the parents after a follow-up period of between four and eighteen years.[52] The US survey of paediatricians cited earlier highlighted similar problems: the specialists were found to be liable to underestimate premature neonates' survival chances and chances of growing up without serious disability. The shorter the pregnancy, the more seriously the paediatricians were to underestimate the baby's prospects. Of those born after twenty-three weeks, the doctors estimated that only 18 per cent would ultimately have no serious disability, whereas in fact 40 per cent grew up free of such disability.[34]

Further research is required into the way that doctors assess the health prospects of neonates.

6.3 Matters of principle

The lack of consensus regarding long-term health prognoses for neonates may to some extent reflect differences of opinion surrounding the practicalities of developing medical prognoses and using them to make long-term health prognoses, but may also reflect disagreements over the principles underpinning the operationalisation and prioritisation of the five key points referred to above. Therefore, in the interests of clarity regarding the way in which the grave long-term health prognosis criterion should be applied in practice, it is important that the implications and relative weighting of each point are precisely defined.

When considering whether a given adverse state of health allows an infant at least a tolerable quality of life, it is not sufficient to compare the infant's life with that of a healthy counterpart. What matters is whether, if the infant were able to choose, he or she would prefer death to life.

To make such an assessment, it is necessary to consider what life, in the relevant adverse state of health, has to offer, and weigh that up against the suffering that the infant is likely to experience. The conditions from which an infant suffers can influence quality of life in various ways. A serious mental disability, for example, may impair the infant's long-term ability to participate in normal life, but need not necessarily entail suffering (e.g. because the child is unaware of being impaired). By contrast, physical disabilities that imply considerable dependency on medical assistance do often contribute to suffering. It is desirable that these various considerations are explicitly addressed in the context of the decision-making process.[44,45,53]

It is important that the assessment is made from the patient's perspective as far as possible. This implies avoiding any conscious or unconscious bias in favour of normalcy, i.e. appraising the implications of a condition from the perspective of a healthy person, such as the doctor him/herself. Against this background, the anticipated degree of suffering may, for example, be regarded as an obvious focus point, albeit that the anticipated capacity for communication is important primarily in the context of the patient's ability to form meaningful relationships and that it is necessary to argue for restrictive interpretation of the self-sufficiency criterion.[44,54,55]

More precise operationalisation and prioritisation of the focus points should be preceded by debate, preferably on the basis of concrete casuistry. The relevant issues have yet to be examined on this basis. In the cases of neonatal life termination reported by doctors that did not lead to prosecution between 1997 and 2004, low levels of anticipated self-sufficiency were among the grounds for intervention. However, no hard facts have been published, with the result that the cases have barely contributed to standardisation. The Expert Committee could address this matter.

6.4 Paucity of scientific evidence

Where factual issues are concerned, it is desirable that long-term health prognoses and forecasts regarding the functional implications of such prognoses are made on the basis of published scientific evidence and expert opinion. Given the inherent value of life, a doctor should not terminate a life unless it can be demonstrated that he or she has a duty alleviate or prevent suffering, which outweighs his/her duty to preserve life. The scientific defensibility of neonatal life termination is of particular importance where the primary motive is the prevention of future suffering.

Scientific evidence that is potentially relevant in the context of life-prolonging treatment and life termination might be obtained from, for instance, research into the development of children born with serious health problems. However, very little follow up-research of this kind has been conducted. So far, such research has largely been restricted to studies of premature neonates, such as the Dutch POPS study and the British EPICure study.[50,56-59] From these studies, it is apparent that premature birth is clearly related to a raised risk of developmental disorders and disabilities. However, serious disabilities are much less common than might be

supposed, partly because the chances of an extremely premature baby with a serious disability surviving are slim. Furthermore, once they are old enough to express an opinion, people who were born prematurely tend to have a more positive view of their quality of life than the people responsible for their care. More precise assessment of a premature neonate's future quality of life is not generally possible. The APGAR score, for example, has been found to have no predictive value in this context, and the predictive value of neurological assessment (MRI, ultrasound scanning) is apparently modest.[50]

Since the quality of decision-making regarding life-prolonging treatment and life termination depends partly on the availability of scientific evidence, more follow-up research is desirable.50 The medical profession could also contribute by investigating the scope for using the findings of such research as the basis for guidelines relating to particular conditions. The Lorber criteria serve as a useful example in this context. These criteria are intended to support doctors making non-treatment decisions in neonatal spina bifida cases, and were developed by reference to the findings of follow-up research that revealed that people with spina bifida considered their lives worthwhile, despite sometimes serious disabilities.*

6.5 Inherent uncertainty

Follow up-research cannot remove all the uncertainties associated with end-of-life decisions involving neonates. Such research can provide only statistical evidence regarding the likelihood of certain health-related developments; positive or negative individual variation will always be possible. It is probably possible to make predictions with a relative high degree of certainty regarding certain specific aspects of a neonate's future health, such as continence or the ability to see or walk. The problem comes with forecasting the implications for the quality of life experienced by the patient. The objectivity of judgements about a neonate's future quality of life can be enhanced by referring to scientific data, but there is likely to remain some degree of subjectivity in many cases.

Because of the inherent uncertainties associated with the prediction of a neonate's future quality of life, there will always be tension between, on the one hand, the need for an objective basis for decisions regarding life-prolonging treatment or life termination in the case of a neonate who is believed to have a grave long-term health prognosis and, on the other hand, the availability of information that can provide such a basis. In view of the inherent value of life, the existence of this tension constitutes a good reason for taking a cautious approach when considering whether to withhold or withdraw life-prolonging treatment or whether to terminate the patient's life. This is not to diminish the ethical and legal principle that medical treatment that may not be expected to benefit the patient is inappropriate and should be terminated.

* A Nijmegen-based research team is currently engaged in research with a view to updating the criteria.[18,50]

Finally, it is important to acknowledge that a neonate's future quality of life depends partly on the care and support available to the child and its parents. However, there is usually an element of uncertainty on that score too. If society does not wish end-of-life decisions to be taken partly on the grounds of fear that sufficient care and support may not in future be available to children with health problems and their parents, it needs to take steps to guarantee the availability of such care and support.

7 Alternatives to life termination

One of the assessment criteria formulated for the Expert Committee is that the doctor and the parents have collectively concluded that there is no other reasonable means of resolving the situation. This implies that there was no way of alleviating the neonate's suffering that was morally less problematic than life termination. However, in the debate surrounding neonatal life termination, relatively little attention has been given to alternative means of alleviating the suffering of neonates with very serious problems.

One option that should be considered is palliative sedation. This involves reducing the patient's consciousness as death approaches and is usually accompanied by the withdrawal of artificial nutrition and hydration.[12,60] However, palliative sedation is regarded as normal medical practice (and therefore acceptable) only in situations where death is expected in the next one to two weeks. Under such circumstances, the administration of sedatives will not materially influence the time of death.[60] The need for death to be imminent implies that this approach is not a practical alternative to life termination in all cases.

In the context of debate regarding the suitability of palliative sedation as an alternative to adult euthanasia, it has been argued that death while unconscious may be at odds with the values embraced by the dying person.[12] However, this argument does not apply in the case of a neonate who has yet to develop any personal value structure. Of greater importance is that opting for palliative sedation rather than life termination is liable to protract the infant's death. The sedated child will not be personally disadvantaged by such protraction,* but the parents and medical staff may find the child's lingering death distressing.**

Finally, a more cautious approach to the initiation of treatment can reduce the likelihood of a situation arising where a neonate with very serious health problems is no longer dependent on treatment for survival*** and thus where life termination may have to be considered. However, as indicated earlier, the desirability of greater caution in such matters is debatable.

* However, compare Verhagen *et al* 2005: If a neonate needs to be so heavily sedated as to show no response to his/her environment or is comatose ... and such sedation needs to be maintained until the infant's death, it is reasonable to assume the existence of intolerable suffering that cannot be alleviated. Keeping a neonate in a comatose state until its death should never be a treatment aim.[61]

** This was also a consideration for the Amsterdam High Court in the Prins case.[3]

*** The Netherlands already differs from other European countries in its treatment of premature infants; Dutch doctors are more cautious about treating those neonates born before the twenty-fifth week of pregnancy.[29,50]

These alternatives to life termination should be taken into account in the context of further standpoint definition.

8 Late abortion

The Expert Committee's role involves reviewing not only neonatal life termination cases, but also certain cases of abortion performed after the twenty-fourth week of pregnancy. Uncertainties exist regarding the practice and regulation of late abortions, similar to those that surround neonatal life termination.

8.1 Foetal conditions

Advances in the field of diagnostics mean that it is increasingly possible to establish in the first twenty-four weeks of pregnancy whether a foetus is affected by a serious condition. Late abortion may be considered only if a serious foetal condition is discovered after the twenty-fourth week pregnancy. Such a discovery will usually be based on ultrasound scanning triggered by the obstetric observation of, for example, retarded growth, excessive amniotic fluid or premature contractions.

It is assumed that a baby born after the twenty-fourth week of pregnancy is ordinarily capable of living outside its mother's womb, albeit sometimes with medical assistance. Hence, the termination of a pregnancy beyond that stage is in principle a criminal offence, being contrary to article 82a of the Penal Code. However, if a foetus has an untreatable condition, such that it is fully expected to die during or immediately after birth, article 82a of the Penal Code does not apply. Under such circumstances, termination of the pregnancy is not a criminal offence, provided that the requirements set out in the Abortions Act are met (article 296, clause 5, of the Penal Code).[17] The Netherlands Association for Obstetrics and Gynaecology (NVOG) has drawn up guidelines on the performance of late abortions in cases of foetal abnormality inconsistent with postnatal viability. Examples of such abnormalities include pulmonary hypoplasia, renal agenesis, trisomy-13, trisomy-18 and anencephaly. The guidelines provide for case review by an NVOG committee.[62]

8.2 Conflicting duties

If a pregnant woman requests a late abortion on the grounds of a serious foetal condition, but the foetus is considered capable of survival outside the womb, the doctor can be confronted by a situation that constitutes an emergency. This is mainly likely to occur if the foetus has a condition that is serious and liable to lead to incurable functional disorders. The NVOG cites

serious forms of spina bifida and hydrocephaly as examples of such conditions.[62] The duties of a doctor confronted by such a case are in conflict. On the one hand, the doctor has a duty to protect the life of the unborn child, but on the other he or she has a duty to assist the mother and a duty to alleviate or prevent the suffering of the foetus. Under such circumstances, the doctor who performs a late abortion may justify his/her action on the grounds of *force majeure* in the form of an emergency situation.[17,63]

A doctor is legally required to report a late abortion to the coroner as an unnatural death, and the coroner has to pass the information on to the Public Prosecutor.[63] So far, however, very few cases have been reported, with doctors either interpreting the foetal deaths as natural or choosing to ignore the reporting requirements because of concerns about the legal implications.[64]

8.3 Review

The low level of reporting is a particular concern where the late abortion of viable foetuses is concerned. It is anticipated that the review of such abortions by the Expert Committee can improve this situation. Since establishment of the Committee, the procedure has been for the coroner to report cases not only to the Public Prosecutor, but also to the Committee, whose review findings are taken into account by the Public Prosecutor when deciding whether to prosecute. If the doctor is considered to have failed to exercise due care, the Committee's findings are also forwarded to the Health Care Inspectorate.

According to the State Secretary for Health, Welfare and Sport and the Minister of Justice, the Committee may conclude that a doctor has exercised due care in the late termination of a pregnancy if all the following conditions are met:

1 Treatment of the foetus's condition following birth would have been medically futile and there was no doubt concerning the diagnosis or associated prognosis; this implies that continuation of the pregnancy offered no prospect of a more accurate diagnosis.
2 The foetus was suffering hopelessly or was expected to do so.
3 The mother expressly requested termination of the pregnancy because of the physical or psychological burden placed upon her by the situation.
4 The doctor properly informed the parents about the diagnosis and prognosis and they collectively concluded that there was no other reasonable means of resolving the situation.
5 The doctor consulted at least one other independent doctor or treatment team.
6 The abortion was performed with appropriate medical care.[10,11]

In the formulation of these assessment criteria, the State Secretary and Minister have drawn upon the views expressed by or in collaboration with representatives of the medical profession, particularly in the NVOG's *Nota late zwangerschapsafbreking* (*Policy Document on Late Abortion*)[65] and in the Consultative Group on Late Abortion's report *Late zwangerschapsaf-*

breking: zorgvuldigheid en toetsing (*Late abortion: the Exercise of Due Care and Case Review*).[63]

8.4 Clinical practice

Very little systematic research has been conducted into late abortion practices in the Netherlands. The only study was performed by the Health Care Inspectorate in the Province of North Holland between 1990 and 1994.

All the cases of late abortion in North Holland involved serious foetal conditions. A condition of the central nervous system (e.g. anencephaly, hydrocephaly, spina bifida or encephalocele) had been discovered in 44 per cent of cases and a chromosomal abnormality (e.g. trisomy-13 or trisomy-18) in 21 per cent of cases. Other cases involved urinary tract abnormalities (13 per cent), skeletal abnormalities (11 per cent) and heart abnormalities (3 per cent).

The doctors who participated in the survey were asked to classify the abortions they had performed on the basis of the system put forward in the NVOG policy document. Their responses indicated that the doctor regarded treatment as having no prospect of success in 79 per cent of cases, since there was no chance of survival or the foetus's postnatal life expectancy would have been very short. In 16 per cent of cases, it was considered that the child would have had a chance of survival if life-prolonging postnatal treatment had been provided, but such treatment was considered hopeless or even harmful. Finally, in 1 per cent of cases the foetus was considered capable of life outside the womb even without treatment, but the doctor believed that life termination would have been considered because of the very poor quality of life the child was expected to face.

In cases where it was expected that, without intervention, the pregnancy would result in a live birth, the doctor anticipated that the baby's life expectancy would be a matter of minutes (e.g. where Potter's syndrome had been diagnosed), a matter of hours or days (e.g. with anencephaly), a matter of weeks or months (e.g. with trisomy-18) or possibly several months to a few years (e.g. with hydrocephaly). In cases where the foetus was not considered viable, it was by no means always clear when foetal death was likely to occur.

Upon termination of the pregnancy, the foetus was stillborn in 80 per cent of cases. The live-born individuals all died within twenty-four hours, 3 per cent after the administration of euthanatics.[63,64,66]

Extrapolation of the North Holland findings indicates that, in the Netherlands as a whole, 150 pregnancies a year are terminated after the twenty-fourth week.[63] Assuming that 20 per cent of the foetuses concerned are viable, roughly thirty cases of potentially criminal late abortion a year should be referred to the Expert Committee for review.

It is by no means certain, however, that the North Holland data remain an accurate reflection of the current situation. Gynaecologists believe that the incidence of late abortion has dropped significantly since the 1990s. Certainly far fewer cases are being referred to the NVOG committee responsible for reviewing late abortions involving abnormalities serious enough to make the foetus non-viable.* On the other hand, more pregnancies are now being terminated between the twentieth and twenty-fourth weeks.** These trends may reflect the increased scope for diagnosing serious conditions much earlier in pregnancy. The introduction of a routine ultrasound scan at twenty weeks is also likely to have contributed to the decline in late abortions.

In view of the situation described above, new research into the way doctors arrive at late abortion decisions is desirable. Such research would also be valuable in connection with the previously mentioned observation that doctors differ in their assessment of the viability of foetuses with multiple abnormalities.[35]

8.5 Acute or anticipated hopeless suffering

The Expert Committee's assessment criteria indicate that late abortion in a case involving a foetal condition that, although serious, does not impinge upon the foetus's viability is permissible only if necessary to prevent acute or anticipated hopeless suffering.

In this context, 'acute suffering' implies the presence of foetal pain.[10] It is assumed that a foetus is capable of feeling pain after about twenty-nine weeks. Because many questions still exist regarding the perception of pain by foetuses and the feasibility of gauging the seriousness of such pain,[50,67] additional research into this matter is desirable.

According to the State Secretary for Health, Welfare and Sport and the Minister of Justice, the prospect of hopeless future suffering may be assessed by reference to the same five focus points used in long-term health prognosis for the purpose of supporting decisions regarding the provision of life-prolonging treatment to neonates and neonatal life termination.[10] The points made in section 6, are also applicable in this context.

* Personal communication from the Committee Late abortion NVOG.

** The Health Care Inspectorate's Abortion Register indicates that between 1996 and 2005, the annual number of abortions performed between the twentieth and twenty-fourth weeks more than doubled, from 514 to 1,178.

9 Policy and research topics

In view of the considerations described above, the following policy and research topics warrant attention.

— There is widespread consensus in the Netherlands concerning the acceptability of life termination in an emergency situation that arises following a justified non-treatment decision. However, there is no general consensus regarding life termination outside the context of life-prolonging treatment, although it has become increasingly apparent in recent years that medical dilemmas concerning life termination can also arise outside the context of life-prolonging treatment. Hence, there is a need for further standpoint definition and for the medical profession as a whole to update its position on this matter.
— In the interests of transparent decision-making, and for other reasons, it is desirable that the legal definition of life termination – the administration of a substance with the aim of hastening death, whether following a decision to withhold or withdraw (potentially) life-prolonging treatment, or under other circumstances – is applied, both in the context of ethical debate and in the context of research into clinical practices. Within this definition, more precise classification is possible on the basis of the particular features of the case, such as the neonate's health status, the factors considered by the doctor and (where relevant) the nature, dosage and duration of the medication administered. Because little is presently known about such features, appropriate additional research is desirable.
— Clarity as to whether acute suffering is always a precondition for the acceptability of life termination is desirable. In the context of neonatal life termination, acute suffering is the principal cause of medical emergencies that must be addressed. However, it is not inconceivable that a situation might arise, in which a doctor felt that his/her duty to prevent serious suffering outweighed his/her duty to preserve life. In addition, further research is needed into neonates' perception of pain, and into the measurement and management of neonatal pain.
— Further standpoint definition is desirable regarding the implications and relative significance of the focus points for the formulation of long-term health prognoses for neonates (the anticipated degree of suffering, life expectancy, the seriousness of the available treatments, the anticipated ability to communicate, the anticipated degree of self-sufficiency and the anticipated degree of dependency on medical assistance). It would also be helpful to have a better understanding of the way in which doctors assess whether a neonate is liable to develop a serious disability. Furthermore, in view of the desirability of basing long-

term health prognoses on scientific evidence as far as possible, more research is needed into the lives of children born with very serious health problems. It is also advisable that the medical profession should look into the possibility of using the findings of such research as the basis for developing guidelines on the formulation of decisions in connection with conditions of various types. However, there is inevitably a degree of uncertainty attached to any assessment of a neonate's future quality of life. Consequently, doctors need to be cautious when considering either withholding/withdrawing life-prolonging treatment or life termination on the grounds of future life quality. This is not to diminish the ethical and legal principle that medical treatment that may not be expected to benefit the patient is inappropriate and should be terminated.

— Further standpoint definition is desirable with regard to the alternatives to neonatal life termination, in particular palliative sedation and a more cautious approach to the commencement of life-prolonging treatment.
— A number of similar recommendations may be made regarding late abortion. For example, more research into the clinical practice of late abortion is desirable and the scope for objective assessment of a foetus's long-term health prospects needs to be increased.

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Appendix 1

Composition of the Standing Committee on Medical Ethics and Medical Law

Professor J.A. Knottnerus; Health Council, The Hague, *president*
Professor J.K.M. Gevers, professor of medical law; AMC, University of Amsterdam, *vice-president*
Dr G.C.M.L. Christiaens, gynaecologist; University Medical Centre, Utrecht
Professor J.C.J. Dute, professor of medical law; University of Maastricht
Professor R.P.T.M. Grol, professor of quality enhancement and monitoring in general medical practice; St Radboud University Medical Centre, Nijmegen
Professor G.R.J. de Groot, professor of medical insurance law; VU University Amsterdam
Professor H. Jochemsen, professor of medical ethics; Professor GA Lindeboom Institute, Ede (from 12 December 2006)
Professor J.C.J.M. de Haes, professor of medical psychology; AMC, University of Amsterdam
R.M. den Hartog-van Ter Tholen, Ministry of VWS, The Hague, *adviser*
Professor G.A. den Hartogh, professor of ethics; University of Amsterdam
Professor A.C. Hendriks, professor of medical law; University of Leiden / medical lawyer; Commission for Equal Treatment, Utrecht
Dr W.L.M. Kramer, paediatric surgeon-paediatric traumatologist; Wilhelmina Children's Hospital, University Medical Centre, Utrecht
Professor F.E. van Leeuwen, professor of epidemiology; Dutch Cancer Institute, Amsterdam
Professor J. Legemaate, professor of medical law; VU University Amsterdam / medical lawyer; KNMG, Utrecht
Professor M.A. Verkerk, professor of medical ethics, University Medical Centre, Groningen
Professor M. de Visser; Vice-president of the Health Council, The Hague
Professor G.M.W.R. de Wert, professor of biomedical ethics; Institute of Health Ethics, University of Maastricht
Professor D.L. Willems, professor of medical ethics; AMC, University of Amsterdam
A. Bood; Health Council, The Hague, *scientific secretary*
Dr W.J. Dondorp; Health Council, The Hague, *scientific secretary*

External experts consulted

M.P. Amelink-Verburg; Health Care Inspectorate
Dr A. van der Heide; Erasmus Medical Centre
A.A.E. Verhagen; University Medical Centre, Groningen
G.G. Zeeman; University Medical Centre, Groningen