

# 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 health 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.