Clear criteria for medical end-of-life decisions for newborn infants with very serious birth defects

The birth of a baby with very serious birth defects may cause difficult dilemmas for parents and medical teams related to the question whether to continue or withdraw treatment. The Royal Dutch Medical Association (KNMG) has published a viewpoint on 'Medical end-of-life decisions for newborn infants with very serious birth defects' which provides guidelines to doctors on what to do when further treatment of a baby offers no medical benefit. The viewpoint sets out the doctors' decision-making process in assessing end-of-life care for seriously ill infants to provide clarity for parents and society. It indicates which medical treatment is considered as proper palliative care and what appropriate end-of-life care can be expected to involve.

Around 175,000 babies are born each year in the Netherlands. Most of them are perfectly healthy, but around 650 infants will die, usually as a result of very severe congenital defects and in spite of the best possible intensive care treatment. This viewpoint sets out a professional standard for the treatment of newborn infants with very serious birth defects where their suffering is extreme and where further life prolonging treatment would be considered medical futile. These are babies who in spite of very intensive treatment are certain to die in the short term, babies with a poor prognosis and very poor expected quality of life, or babies who are not dependent on intensive treatment but who face a life of severe suffering with no prospect of improvement. In these situations, doctors and parents have to face the extraordinarily difficult question whether providing or continuing treatment is actually benefiting the child, or whether that treatment is prolonging suffering and disability and can therefore be seen as causing harm. The position paper has been drawn up with significant input from paediatricians, nurses, and legal and ethical experts.

Core position

Where further treatment is deemed medically futile, treatment is no longer justified. That is the core position. Doctors will inform the parents and explain to them that this also means that the artificial administration of fluids and nutrition will be stopped to prevent the unnecessary prolonging of suffering and the dying process. This position is based both on trust in the medical profession, and on the love of parents for their newborn child. Doctors will allow parents time to come to terms with the decision, yet within reason. This is because the doctor's primary duty of care is towards the infant, and the treatment provided must not harm or prolong harm or suffering. Their duty is then to provide good palliative care.

Palliative care and deliberate ending of life

The viewpoint aims to put an end to any uncertainty about the various decisions in relation to the end of life of newborns and the criteria for deliberate ending of life. The position paper makes it clear that it is crucial for parents to be properly informed and involved in the process, and that palliative care, including palliative sedation, can greatly relieve suffering. But sometimes that is not enough. Once the decision has been made not to provide treatment, or to withdraw it, there may be a justification for the use of muscle relaxants within the context of the dying process: if they were already being provided as part of treatment, if a newborn infant is gasping for breath or if their inevitable death is proving unbearable for the parents. The viewpoint helps to set out a transparent decision-making process, and such a process is clearly in the interests of the medical profession and society as a whole. Having clear criteria helps doctors to focus on the quality of life and death of newborns and dispels anxiety around possible prosecution. It also provides clear benchmarks for bodies such as the Health Care

Inspectorate, the Central Committee of Experts on Late-term Abortion and Termination of Infants, and the Public Prosecution Service.

Further details on parts of the position paper

A brief explanation of parts of the position paper is provided below:

Decision making and the role of parents
Doctors are expected to communicate with parents openly, directly and regularly. Parental input is a vital part of the decision-making process, particularly where the prognosis is uncertain. Parental permission is always required for the treatment of a newborn baby. Where treatment is medically futile, doctors may – following consultation – decide independently to suspend or to not provide such treatment. This is because the doctor's primary duty of care is towards the infant, and the treatment provided must not harm or prolong harm or suffering.

Suspending nutritional support
If there is no longer any justification for providing life-prolonging treatment to a baby, it will also be unacceptable to continue administering fluids and nutrition. Doctors may allow parents time to understand and accept as best they can that treatment is to be suspended, but there will be a time limit to how long parents' desire to continue treatment can be accommodated, once it has been established that such treatment is medically futile.

Gasping and administering of muscle relaxants
Newborn infants may be visibly suffering if they are gasping for air. Once it has been decided to withhold further treatment, the position paper states that the administering of muscle relaxants is justified where:

- the baby is gasping, visibly suffering, and pain relief is not sufficiently effective. Deliberate ending of life will then be justified and must be reported to the Central Committee of Experts for assessment. The position paper provides a clear framework for subsequent assessment of the appropriateness of this action;

- if the dying process is underway but is so prolonged that it is causing serious distress to the parents. Such a situation must also be reported. Justification on these grounds needs to be added to the criteria under the Regulation for the Central Committee of Experts;

- if the baby was already receiving muscle relaxants as part of its treatment.
Continuing the administering of this treatment may be regarded as normal palliative care if suspending it and waiting for it to wear off is deemed unsuitable, for instance in the interests of preventing serious discomfort or to ensure that the infant can die in his/her parents' arms. Its purpose is not to end life and thus it need not be reported to the committee of experts. This would constitute a natural death and the municipal forensic pathologist is not required to report it to the Central Committee of Experts.
