Review Committee
on Late-term Abortions and Neonatal Termination of Life

Annual report 2016

Contents

1. Foreword

This is the 2016 annual report of the Review Committee on Late-term Abortions and Neonatal Termination of Life ('the Committee'). The Committee was established on 1 February 2016 by the Minister of Health, Welfare and Sport and the Minister of Security and Justice. This is its first annual report.

The Order establishing the Review Committee on Late-term Abortions and Neonatal Termination of Life (Government Gazette 2016, 3145; 'the Order') entered into force on 1 February 2016. The Order amended the legislation establishing the Central Committee on Late-term Abortions and Termination of Life (Neonates) (Government Gazette 2007, 51). The revised legislation was the result of an evaluation of the previous Order published in September 2013, and the government's position on this evaluation published in July 2014. The evaluation report, the new Order and the circumstances that led to them were discussed in detail in the Central Committee's final (2015) annual report.

The current Order sets out the applicable due care criteria in greater detail and clarifies a number of medical and legal issues. It extends the review procedure to cover cases in which it may reasonably be expected that the unborn child cannot live outside the mother's body, known as 'category 1 late-term abortions'.

In this reporting period the Committee received three notifications of late-term abortion and no notifications of neonatal termination of life.

This annual report discusses the Order, the Committee's role and the notifications received by the Committee.

Professor Eva Pajkrt
Chair

16 May 2017

2. Legal framework

2.1 General

As of 1 February 2016, the Committee assesses whether due care was exercised by physicians carrying out a category 1 or 2 late-term abortion or neonatal termination of life as laid down in the Order.

Definitions

'Late-term abortion' means a procedure that is intended to terminate a pregnancy of more than 24 weeks involving a viable fetus, with the aim of ending the life of the fetus, on account of severe fetal disorders.

A 'category 1 late-term abortion' is a case in which it may reasonably be expected that the unborn child cannot live outside the mother's body. The fetus is suffering from an untreatable condition which is expected to lead inevitably to death during or directly after birth.

A 'category 2 late-term abortion' is a case in which the unborn child is suffering from a condition which will lead to severe and irreversible functional disorders, or one in which the unborn child has little reasonable chance of survival.

'Neonatal termination of life' means the deliberate shortening of a newborn infant's life where the child is suffering unbearably and is without prospect of improvement (current suffering) or can be expected to suffer unbearably and have no prospect of improvement in the future (future suffering). The child's state of health precludes any prospect of an independent life.

'The physician' is the doctor who performs the procedure that leads to a late-term abortion or termination of life of a neonate. In many cases this is the lead attending physician. In the event that the lead attending physician instructs another physician, a registrar or another care professional involved in the case to perform the procedure, the lead attending physician is accountable for compliance with the due care criteria. This does not apply if the case is transferred to another physician. The latter is then considered to be the lead attending physician and is accountable for compliance with the due care criteria.

A 'neonate' is a child that has not yet attained the age of one year.

A 'notification' is a notification by the physician of a category 1 or 2 late-term abortion or neonatal termination of life to the review committee using the model form.[1]

An 'independent physician' is a doctor who is not attached to the hospital or medical centre where the late-term abortion or neonatal termination of life is performed, who has expertise relating to the condition from which the fetus or neonate is suffering and who has no treatment relationship with the patient.

The 'findings' are the result of the review committee's review of the physician's compliance with the due care criteria in performing a late-term abortion or terminating the life of a neonate.

Review

Performing a category 1 or 2 late-term abortion and terminating the life of a neonate are in principle offences under articles 82a, 289 and 296 of the Criminal Code. Invoking necessity as a justification can however remove criminal liability. Necessity is only present if according to prevailing medical opinion the disorders affecting the child are of such a nature that medical intervention after birth would be medically futile. The Committee determines in light of the due care criteria set out in articles 5, 6 and 7 of the Order establishing the Review Committee on Late-term Abortions and Neonatal Termination of Life whether this is indeed the case.

Due care criteria

Article 5

A physician who performs a category 1 late-term abortion has acted with due care if he has complied with the requirements laid down in the applicable legislation and in prevailing professional standards (Termination of Pregnancy Act and the model protocol of the Dutch Society of Obstetrics and Gynaecology (NVOG)).

[1] Model forms can be downloaded from www.lzalp.nl.

Article 6

In performing a category 2 late-term abortion, the physician has acted with due care if:

a. the physician was satisfied that the unborn child was suffering from a disorder or a combination of disorders of such a nature that medical treatment would be withheld after birth on the grounds that intervention was futile according to prevailing medical opinion, and there was no reasonable doubt, according to prevailing medical opinion, regarding the diagnosis and associated prognosis;

b. the physician was satisfied that the unborn child was currently suffering or could be expected to suffer, without prospect of improvement;

c. the physician fully informed the parents of the diagnosis and associated prognosis. This means that together with the parents the physician came to the firm conclusion that there was no reasonable alternative in light of the unborn child's situation;

d. the mother made an explicit request for the pregnancy to be terminated because of physical or mental suffering caused by the situation;

e. the physician consulted at least one other, independent physician, who gave a written opinion on the above due care criteria. Alternatively, if no independent physician could reasonably have been consulted, the physician consulted the attending medical team, which gave a written opinion on the above due care criteria;

f. the pregnancy was terminated with due medical care.

Article 7

In terminating the life of a neonate, the physician has acted with due care if:

a. the physician was satisfied that the newborn child was suffering unbearably and without prospect of improvement, which means, *inter alia*, that the decision to withhold medical treatment was justified; in other words, it was established that intervention would be futile according to prevailing medical opinion, and there was no reasonable doubt, according to prevailing medical opinion, regarding the diagnosis and associated prognosis;

b. the physician fully informed the parents of the diagnosis and associated prognosis and together with the parents came to the firm conclusion that there was no reasonable alternative in light of the unborn child's situation;

c. the parents gave their consent for the termination of life;

d. the physician consulted at least one other, independent physician, who gave a written opinion on the above due care criteria. Alternatively, if no independent physician could

reasonably have been consulted, the physician consulted the attending medical team which gave a written opinion on the above due care criteria;
e. the termination of life was performed with due medical care.

No duty to notify the Committee when a late-term pregnancy is terminated for reasons relating to the mother's health

Terminating a pregnancy after 24 weeks as a necessary and only possible response to a serious medical condition presenting in the mother constitutes acceptable, appropriate and unavoidable medical treatment. In general, such a termination will be covered by the legal justification of necessity, which means the physician is not criminally liable. The ministers saw no reason to have such cases reviewed in the context of terminations on grounds of the health of the child and there is thus no need to notify the Committee.

However, should the fetus die, this must be reported, like any other such death, to the municipal pathologist, who in turn informs the public prosecutor. In addition, the Health and Youth Care Inspectorate (IGJ) has a supervisory role. In the event of a serious breach of professional standards the inspector can send a report to or lodge a criminal complaint with the Public Prosecution Service. In that case and in the event that the public prosecutor receives a criminal complaint or report from another source, the Public Prosecution Service has a role to play. In all other cases of late-term abortion for reasons relating to the mother's health, the public prosecutor's role is confined to assessing the request for permission to bury or cremate the child.

2.2 Procedures and the Committee's findings

If the decision has been made to perform a late-term abortion or terminate the life of a neonate, the physician informs the parents of the procedures involved. The parents need to consent to the procedures and to the sending of the relevant case file to the competent authorities. If the parents do not give their consent for this, the physician may decide not to proceed.

The physician notifies the municipal pathologist that he or she has performed a category 1 or 2 late-term abortion or has terminated the life of a neonate. The municipal pathologist carries

out an external postmortem and determines how and with what substances the termination was carried out. The municipal pathologist then contacts the public prosecutor, who gives permission for burial or cremation. The pathologist plays no further role in the notification procedure. The physician sends the completed model reporting form and all relevant supplementary documentation to the Committee.

Within six weeks of receiving the notification the Committee sends its written findings to the physician and, in the case of a category 2 late-term abortion or neonatal termination of life, to the Board of Procurators General ('the Board'). The six-week period can be extended by a maximum of six weeks.

Authoritative opinion

The Committee's findings have the status of an authoritative opinion issued to the Board. The latter nevertheless reaches a final decision concerning category 2 late-term abortions and neonatal termination of life.

Category 1

If the Committee concludes that a category 1 late-term abortion has been performed in compliance with the due care criteria, that means the case has been disposed of. If it decides that the physician has not acted in accordance with the due care criteria, it sends its findings to the Health Care Inspectorate. The Inspectorate may decide to conduct an investigation to determine whether and, if so, what measures should be taken in respect of the physician.

Category 2 and neonatal termination of life

If the Committee concludes that a category 2 late-term abortion or neonatal termination of life has been performed in compliance with the due care criteria, it sends its findings to the Board of Procurators General, which may decide not to prosecute. If the Committee decides that the physician has not acted in accordance with the criteria, it sends its findings to the Board and to the Health Care Inspectorate. These bodies then decide according to their own competence and responsibility whether and, if so, what measures should be taken in respect of the physician.

2.3 Legal scrutiny and final decision of the Board of Procurators General

The Committee believes it is important to explain in greater detail the Board's scrutiny and final decision regarding category 2 late-term abortion and neonatal termination of life.

Criminal liability

The Board assesses a physician's criminal liability relating to a late-term abortion or neonatal termination of life, with advice from the Expertise Centre on Medical Affairs (EMZ). If the physician has complied with the due care criteria, he or she is not criminally liable. The Board will then decide not to prosecute.

For many physicians category 2 late-term abortions and terminating the life of a neonate are difficult issues. These are often complex cases that confront the physician with intractable ethical considerations. The procedures surrounding termination cost time and energy and there is legal scrutiny based on criminal law (articles 82a, 286 and 296 of the Criminal Code). The ethical, social and political sensitivity of the issue makes it imperative that physicians' actions are transparent and subjected to review.

> ***'If the profession as a whole can arrive at common standpoints with regard to these issues, they then become part of medical professional standards.'***

The Order defines the boundaries within which physicians' actions in relation to late-term abortion and neonatal termination of life must take place. In brief, the physician's actions must be in conformity with medical professional standards. Insight into the cases which have undergone legal scrutiny can contribute to the development of medical knowledge within the profession. Issues giving rise to discussion become more transparent. If the profession as a whole can arrive at common standpoints with regard to these issues, they then become part of medical professional standards.

Serious breaches of the due care criteria or abuses will be subject to further criminal investigation, which may lead to prosecution. To date, the Board has not instituted criminal proceedings in any of the notifications it has reviewed.

Instructions

Further information on what decisions the Board may make and the circumstances that may give rise to prosecution can be found in the Instructions on Prosecution Decisions in the Matter of Termination of Life Not on Request and Late-term Abortions. At the time of writing the (new) Instructions had not yet entered into force. Once this is the case, they will be published on the Committee's website.

Evaluation

The Board and the Committee conduct an annual evaluation of the notifications received. Being determined by the specific circumstances, each case is unique. Should a case give rise to questions (for example, certain difficulties experienced) the Committee and the Board will consult with each other and suggest possible solutions. These solutions will then be considered and if necessary further developed by those involved.

3. The Committee's activities in 2016

3.1 Notifications

In 2016 the Committee received three notifications of late-term abortion. Two of these fell in category 1 and one in category 2. There were no notifications of termination of the life of a neonate. This was the first year that the Committee reviewed cases of late-term abortions in both categories 1 and 2.

The Committee is aware of the low number of notifications of late-term abortions and termination of the life of neonates. In this context it refers readers to the annual reports of the Central Committee in previous years. The Committee hopes that the entry into force of the Order on 1 February 2016 will provide clarity to physicians with regard to how the due care criteria should be interpreted in difficult cases and the procedure to be followed.

3.2 The Committee's role

The Committee is fully aware of the ethical, professional, social and legal difficulties that late-term abortions and neonatal termination of life present for physicians and parents. In addition to its statutory review task, the Committee believes it has a role to play in promoting understanding and improving clarity and transparency in these two areas. To this end, the Committee defines its task as follows:

'The aim of the Order establishing the Review Committee on Late-term Abortions and Neonatal Termination of Life is to enable physicians to end suffering without prospect of improvement in unborn or newborn infants that is unbearable or is expected to become unbearable. This must always be preceded by considered decision-making and application of the established criteria, followed by careful review. The latter is the Committee's task. By being clear and transparent regarding its procedures and findings, the Committee aims to encourage physicians to report these cases. Clarity and transparency help build public confidence. It is absolutely vital that practice in matters as sensitive as these is supported by society and the medical profession. Insight into the procedures followed is essential to establishing best practices providing high-quality care for parents and children.'

The Committee is regularly asked whether in a specific case it can answer questions beforehand on the procedure to be followed and if this is the correct policy. Since it is the Committee's task to review cases retrospectively, it would be undesirable and indeed impossible for it to answer questions relating to a specific case beforehand.

However, the Committee is available to answer general questions seeking to clarify the procedures and the due care criteria. A representative of the Committee is also prepared to give, in person, further explanations of the Order on request.

The Committee would refer physicians intending to perform a late-term abortion or terminate the life of a neonate to its website (www.lzalp) for further information on procedures, the model reporting form and notified cases.

> ***'It is absolutely vital that practice in matters as sensitive as these is supported by society and the medical profession.'***

4. Notifications and findings

2016

In 2016 the Committee received three notifications of late-term abortions. The Committee considered itself competent to review these notifications and in all three cases came to the conclusion that the physicians concerned had acted in accordance with the due care criteria.

Below the Committee discusses the anonymised notifications. The first two cases involve category 1 late-term abortions and the third a category 2 late-term abortion. The Committee's considerations are included where relevant.

Case 2016/LZA1/01

The report and other information submitted by the physician showed the following.

An ultrasound examination performed at the medical centre when the mother was 27 weeks pregnant revealed that the child was suffering from anencephaly. Previously, the mother had decided not to undergo antenatal screening; she had not had the combined test or a 20-week ultrasound scan. The mother was referred to a university medical centre (UMC), where the physician confirmed the diagnosis and took charge of her treatment.

At 31 weeks and one day of pregnancy, an ultrasound examination again confirmed the presence of anencephaly: the child had no skull or brain tissue. This is a fatal condition. The prognosis was infaust: there was no conceivable favourable outcome for the child. Life expectancy after birth was only a few days.

The physician concluded that the mother was suffering acutely from severe psychological distress due to the knowledge that her child was suffering from a fatal condition and had no prospect of leading a full life.

In view of the infaust prognosis, at 31 weeks and one day of pregnancy the mother requested termination of the pregnancy in the interests of her child and in her own interests. She supported her oral request with a written request which she signed.

The physician and another gynaecologist informed the mother of the diagnosis and prognosis, and discussed the possibility of carrying the child to term. There were no treatment options – either antenatal or postnatal – that would have improved the prognosis.

The decision to terminate the pregnancy was taken after consultations within the multidisciplinary team (MDO). The mother's request was also discussed. The multidisciplinary team consisted of the physician, three other gynaecologists, a gynaecology registrar, two paediatricians and a nurse. There was general agreement on the diagnosis and prognosis and on whether the mother's request should be complied with.

At 32 weeks and five days of pregnancy, labour was induced at the UMC through the administration of prostaglandins. That same day the baby was born alive and was in a reasonably good condition given the circumstances. Morphine was administered to ensure that the child was comfortable. The baby died a day later. An external postmortem confirmed the antenatal findings.

Case 2016 LZA1/02

The report and other information submitted by the physician showed the following.

The mother in this case was pregnant with her second child and was under the care of a midwife. She had a healthy daughter aged eight from a previous relationship, whose birth had been traumatic. The mother had a history of recurrent depressive episodes and a panic disorder for which she was being treated with medication.

At 19 weeks and one day of pregnancy, the 20-week ultrasound scan revealed multiple abnormalities consisting of delayed growth, suspected severe cardiac abnormalities and overlapping fingers. The mother was referred to a university medical centre (UMC1) for advanced ultrasound scanning.

At 19 weeks and six days of pregnancy, the abnormalities were confirmed at UMC1. It was suspected that the child had trisomy 18 (Edwards' syndrome). Amniocentesis confirmed this diagnosis. This is a fatal condition. The prognosis was infaust: there was no conceivable favourable outcome for the child.

Trisomy 18 is most commonly associated with low birth weight, cardiac abnormalities and severe intellectual disability. Most children with trisomy 18 die during pregnancy. If born alive, they often die within a few hours or days. The majority die before they reach the age of one year. Given the fact that growth restriction had already occurred in this child, it was conceivable that it would die in the womb or during labour.

The gynaecologist and the paediatrician at UMC1 informed the mother about trisomy 18. At that point she was 20 weeks and five days pregnant. That same day she was referred to a local hospital to discuss termination of the pregnancy. She stated that the conversations at both UMC1 and the local hospital did not go well and that she had been put under pressure to take the decision to terminate the pregnancy before 24 weeks.

At 22 weeks and one day of pregnancy, the mother had a consultation with a clinical geneticist from UMC1 and a medical social worker, during which trisomy 18 was again discussed. She requested a second opinion and was referred to a different university medical centre (UMC2) to discuss the options of carrying the child to term or terminating the pregnancy.

At 23 weeks and two days of pregnancy, UMC2 provided a second opinion, after an ultrasound examination confirmed the presence of trisomy 18. Again, the options of terminating the pregnancy or carrying the child to term with the provision of palliative care after birth were discussed. The mother also talked to a medical social worker at UMC2.

There were no treatment options – either antenatal or postnatal – that would have improved the prognosis.

In view of the infaust prognosis and the mother's mental health, at 24 weeks of pregnancy the mother and her partner requested termination of the pregnancy at UMC2 in the interests of their child, the mother's interests and those of her family. She supported her oral request with a digital statement.

The physician concluded that the mother was suffering acutely from severe psychological distress due to the knowledge that her child was suffering from a fatal condition. In addition, her mental suffering also consisted of longstanding depression and a panic disorder.

The decision to terminate the pregnancy was taken after consultations within the multidisciplinary team (MDO) at the medical centre. The mother's request was also discussed in the MDO. The multidisciplinary team consisted of the physician, three gynaecologists, a neonatologist, a paediatric cardiologist and a clinical geneticist. There was general agreement on the diagnosis and prognosis and on whether the mother's request should be complied with.

The late-term abortion was performed by the administration of prostaglandins. At 24 weeks and five days of pregnancy mifepristone was administered. Labour was induced at 25 weeks of pregnancy through the administration of misoprostol. The child was stillborn after 15 hours and 27 minutes.

Case 2016/LZA2/01

The report and other information submitted by the physician showed the following.

The mother in this case had no partner. This was very much a wanted pregnancy, following fertility treatment (ICSI) using donor sperm. She was under the care of a medical centre.

At 34 weeks and five days of pregnancy, the mother had an ultrasound examination at the medical centre which revealed a smaller than normal head and vasa praevia. She was referred to a university medical centre.

At 35 weeks and three days of pregnancy, advanced ultrasound scanning showed that the child was suffering from microcephaly, as well as corpus callosum agenesis, pachygyria, ventriculomegaly and extensive intracranial calcifications. These disorders were consistent with a congenital infection.

Advanced ultrasound scanning was repeated several days later and confirmed the results of the first scan. Amniocentesis confirmed the diagnosis of congenital cytomegalovirus infection (CMV). Additional blood cultures and virological tests revealed that the child had contracted a CMV infection during the first trimester.

The prognosis was extremely poor. Postnatal life expectancy could not be predicted with any accuracy. After birth, the child would develop severe cognitive and neuromotor disorders

which in the longer term would very probably threaten vital functions, leading to death. Even if the child was in a reasonably good condition after birth, intensive treatment and care would still be needed.

The prognosis was severe psychomotor retardation accompanied by spasticity, a considerable risk of severe refractory epilepsy, vision and hearing impairment, respiratory problems, and feeding and swallowing disorders.

The information provided by the physician showed that the child was suffering from extremely severe brain abnormalities that would lead to serious disabilities and substantially reduced life expectancy.

There were no treatment options – either antenatal or postnatal – that would have improved the prognosis. Postnatal care would not offer any genuinely different prospects for the child. With regard to the child's expected state of health at a later date in relation to the degree of suffering, the physician stated in the prognosis that intractable complications such as feeding and swallowing disorders, respiratory problems and severe refractory epilepsy could arise.

The physician concluded that the mother was suffering acutely from severe psychological distress due to the knowledge that her child was suffering from an extremely severe, refractory condition and after birth would have severe multiple disabilities with no chance of further development or life prospects. The mother was adamant in her desire to spare her child any possible current or future suffering.

In view of the extremely poor prognosis, at 36 weeks of pregnancy the mother made an oral request for termination of the pregnancy in the interests of her child and in her own interests. She repeated this oral request to the physician and in a conversation with the medical social worker.

The physician and a paediatric neurologist informed the mother of the diagnosis and prognosis on several occasions. The possibility of carrying the child to term and the possible risks associated with vasa praevia were also discussed. Carrying the child to term was not an option for the mother. She was unswerving in her wish to have the pregnancy terminated.

After the physician had informed her about the nature and method of termination, she wanted fetal demise to be induced to spare her child further suffering.

The decision to terminate the pregnancy was taken after consultations within the multidisciplinary team (MDO). The mother's request was also discussed in the MDO. The multidisciplinary team consisted of the physician, three gynaecologists, a paediatric neurologist, two neonatologists, a paediatric nephrologist, a radiologist, two clinical geneticists and an anaesthetist. There was general agreement on the diagnosis and prognosis and on whether the mother's request should be complied with.

The physician also requested a second opinion at another university medical centre (UMC2) regarding the diagnosis, prognosis and request for a late-term abortion. An intake and ultrasound examination were performed for this purpose. The findings were discussed at UMC2 in consultations between a paediatric neurologist, three neonatologists, a paediatric radiologist, three gynaecologists, three perinatologists and a paediatric surgeon.

They agreed unanimously on the diagnosis and prognosis, confirming that the child was suffering from severe microcephaly with extensive calcifications, cysts and a highly abnormal gyral pattern consistent with intrauterine CMV infection early in pregnancy. The child would almost certainly suffer from a severe psychomotor developmental delay, severe refractory epilepsy, vision and hearing impairment and feeding/swallowing disorders, causing significant distress. According to the physicians at UMC2, the child would be expected to have a severe, rather than normal or mild, developmental delay.
The physicians could understand the mother's request for a late-term abortion.

At 37 weeks of pregnancy, fetal demise was induced at UMC1. Prior to this, the physician consulted a perinatologist abroad on the best way of performing the procedure. A muscle relaxant (rocuronium) was administered intramuscularly via the leg and an analgesic (fentanyl) was given, followed after 15 minutes by an intracardial injection of lidocaine 2% (10ml), after which death ensued.

Two days later labour was induced through the administration of mifegyne and misoprostol. That same day the child was stillborn. An external and internal postmortem examination confirmed the antenatal findings.

The Committee's considerations regarding expected suffering without prospect of improvement

The Committee noted that postmortem neuropathological examination of the brain confirmed the nature and extent of the antenatal diagnosis, namely a fetal CMV infection with extremely widespread, severe brain damage and secondary malformations of cortical development. The postmortem examination also provided important support for the prognosis given.

On the basis of the information provided by the physician, the Committee concluded that the child could be expected to experience physical suffering without prospect of improvement consisting of a considerable risk of severe refractory epilepsy, feeding and swallowing disorders, respiratory problems, vision and hearing impairment and substantially reduced life expectancy.

The Committee found that in the long term, the combination of expected disabilities with poor expectations of further development or life prospects for the child in this case could be taken into account when assessing the expected suffering without prospect of improvement.

5. The Committee

The Committee consists of six members. The chair is a physician. Four members are physicians from a number of disciplines related to the issues at hand (gynaecology, neonatology and child neurology) and/or working in those fields. One member is an expert in ethical and moral issues and one is a lawyer. There is an alternate member for each of the members. The Committee is assisted by a secretary.

Members

Professor E. (Eva) Pajkrt, gynaecologist (chair)
A.C. (Mieke) de Die, LLM (lawyer, also deputy chair)
Professor O.F. (Oebo) Brouwer, child neurologist
Professor J.H. (Joke) Kok, neonatologist
F.J.C.M. (Frans) Klumper, gynaecologist
Professor M.A. (Marian) Verkerk, ethicist

Alternate members

Dr A. (Audrey) Coumans, gynaecologist
R.P. (Rolinka) Wijne, LLM, lawyer
Professor M.A.A.P. (Michel) Willemsen, child neurologist
Dr M.A.H.B.M. (Mark) van der Hoeven, paediatrician/neonatologist
Dr G.T.R. (Wendy) Manten, gynaecologist
Professor M.C. (Martine) de Vries, medical ethicist

Secretariat

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