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End of life decisions on severely handicapped fetuses and newborns in the Netherlands*

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In Research Centre for State and Law research papers 01/07 we dealt with new developments on the subject of end of life decisions in the Netherlands, the use of palliative sedation. We wrote that palliative sedation might reduce the number of requests to perform euthanasia and might solve some problems related to euthanasia. Both expectations seem to come true, but there are still a number of problems related to euthanasia which wait for a final solution. One of the problems which call urgently for a solution is related to end of life decisions on a foetus or a new born child with serious and incurable physical defects. We will describe two situations; the situation in which after the delivery the child appears to be severely handicapped and the situation in which before the delivery it is without doubt that the foetus will be severely handicapped.

The first situation is related to newborn babies with very restricted prospects of life or very bad prognosis for their future health. This is for example the case for babies suffering from lung hypoplasia or babies with very serious brain damage like anencephaly. When the physical condition of newborn babies according to present scientific medical insight is such that the baby will surely die within a short period of time after the delivery (a few days till a few months), medical treatment is considered to be useless. In such a case it is an appropriate and medically accepted decision to not start or to further abstain from medical treatment. The death is to be seen as a natural death and not as the result of a decision to terminate life. In order to be sure that further medical treatment is useless, the doctor in charge needs to have a full picture of the present and future health situation of the baby patient. Important elements in this respect are: what level of suffering is to be expected, what is the expected life span, what is the expected burden for the patient of the treatment, what are the expected possibilities of the baby to communicate and what will be his/hers level of dependence of medical care on the longer term?

When the situation in all aspects is seriously negative the start or continuation of medical treatment is useless. Palliative care – even when this would lead to shortening of life – may however be applied. When the newborn baby dies in such a case, there is no obligation to report his death to the coroner because his death is considered to be a natural one.

When in this situation the doctor decides to terminate the life of the newborn, there is a statutory obligation (Burial Act) for the doctor to report this to the coroner, because this is an unnatural death.

The second situation concerns the case that before delivery it is clear that a severely physically defect baby will be born. In this situation it can be de-

cided to have the pregnancy continued and to act after delivery as described above. An alternative for this situation would be that a decision is taken not to continue the pregnancy and to induce an abortion. In the Netherlands, as we have seen in chapter 4, induced abortion is permitted except in cases of late abortion. Induced abortion is ruled by sect. 296 PC and the 1981 Termination of Pregnancy Act.

According to the present state of affairs in medical science, fetuses of 24 weeks and more are considered viable. According to sect. 82a PC, the taking of life as mentioned in sects 287 and 289 PC (homicide and murder) implies the killing of a foetus which – as may in fairness be expected – is able to stay alive outside the mother's body. So, late abortions may cause great problems. They occur when the term of 24 weeks has passed and serious physical defects on the foetus are found after that term. The woman's request for induced abortion because of this deficiency may be a problem.

Two categories of cases may occur.

The first category concerns cases where the foetus's ailment is such that it can medically be assumed that the foetus will die immediately during or shortly after the delivery. In that case there was not an independent viability in the sense of sect. 82a PC and induced abortion, provided that the doctor complied with the rules for induced abortion laid down in the Termination of Pregnancy Act does not constitute a criminal offence (Sect. 296 subs. 5 PC) and no criminal prosecution can be established. Due to the Burial Act a notification of an unnatural death to the coroner and through him to the public prosecutor has to take place.

The Dutch Association for Obstetric and Gynaecology in October 2003 issued a protocol for the consultation procedure to be followed prior to the performance of a late induced abortion. The protocol requires a post facto inter-collegial assessment as well.¹

The second category concerns cases in which the physical defects will cause serious and irreparable dysfunction but nevertheless – as may in fairness be expected – a life expectancy – though restricted – exists. Without medical treatment however the defects will be lethal. Medical treatment will cause life-long suffering and may even be considered detrimental. In these cases the induced abortion falls within the scope of sect. 82a PC and therefore constitutes a crime. The crime may be justified due to necessity (sect. 40 PC) if according to medical insight it is sure that the deficiency of the foetus is so serious that medical treatment after the delivery is medically useless.

The conclusion is that in two situations termination of life of fetuses or newborn babies with serious physical defects, theoretically may constitute a crime of murder, the case in which the doctor (actively) terminates the life of a severely defect baby and the case in which a late abortion is performed on

¹ Medisch handelen late zwangerschapsafbreking bij niet met leven verenigbare afwijkingen vallend onder categorie 1 (Medical performance of late induced abortion in case of defects non-compatible with life), www.nvog.nl/file/model_01_regl_lza_web.pdf.

a foetus with severe physical defects but also with some life expectancy. Due to the unnatural death the doctor is legally obliged to inform the coroner about the unnatural death by filling out a form and by responding to a number of questions. This form is sent by the coroner to the public prosecutor who assesses the termination of life decision and who, when necessary, may decide to give the police instructions to start an investigation.

From the context in which the crime has been committed, it is obvious that this crime is not a regular murder case and for his decision the public prosecutor actually lacks sufficient medical knowledge to properly assess the case.

The deliberate termination of life of severely handicapped fetuses or newborns has been a problem for gynaecologists and paediatricians for several decades in the Netherlands. The problem was that the termination of the life of a foetus or a newborn never falls within the legal scope of euthanasia because for euthanasia there shall be an explicit request to terminate life. Obviously a foetus or a newborn cannot request and parents according to a ruling of the Dutch Supreme Court cannot act in this respect as substitutes. Ever since the first political steps towards the 2001 Termination of life on request and assistance in suicide (review procedures) Act, were put, this problem was discussed, but never solved.

In 1992 this problem was made more public by the report called 'To Act or to Abstain' of the Dutch Society of Paediatrics.² The report made clear that in cases of very severely handicapped newborns incidentally the decision to terminate life was taken. In this report for the first time in Dutch history the possibility of a deliberate termination of the life of severely defected newborns was presented as a medical professional way of handling the case. However, the Dutch Society of Paediatrics recognized that there was no consensus under paediatricians. At the time of the report no figures were available about the frequency in which this occurred and no cases were reported to the public prosecutor.

In 1995 gynaecologist Prins and general practitioner Kadijk were prosecuted for terminating the lives of severely handicapped newborns.

In the Prins case the court of appeal of Amsterdam ruled that the decision to terminate the life of the baby was, in light of the poor prospects for the baby and the suffering it would have to undergo, justified. There was no other medical solution to stop the suffering of the baby. The court held that pain relief while awaiting death would not have been a medical sound treatment. The importance of the fact that the parents 'expressly and in a well-

² Dutch Society of Paediatrics, *To Act or to Abstain. The Limits of Medical Practice in Neonatology*. (Dutch report, containing an English summary), 1992.

considered way' agreed with the doctor's proposed course of action was particularly emphasized by the Court.³

In the Kadijk case the court of appeal of Leeuwarden came to the same conclusion about the termination of the life of a newborn with trisomy 13.⁴ The court ruled that there was no doubt at all about the medical diagnosis and prognosis and both the doctor and the parents were familiar with these, there was no doubt at all about the well-considered consent of the parents to the termination of life, the doctor secured the advice of an independent experienced doctor (GP) and consulted the responsible paediatrician, the doctor brought about the baby's death in a conscientious and careful manner, after having satisfied himself of the correctness of the chosen method and the doctor had given account of his conduct in this matter.

After Prins and Kadijk the Dutch ministry of Health, Welfare and Sport established a group of specialists to discuss the issue of deliberate termination of the life of severely handicapped newborns. In the advice of the discussion group the Kadijk criteria were described more precise.⁵ The criterion of *no hope for recovery* was narrowed to the criterion of *intolerable suffering or facing a degrading death*. The physician should not only ask a colleague for advice, but the second opinion should be asked from an *independent colleague from another hospital*. The decision to terminate a life of a newborn should not be taken solitarily, but the physician should *discuss the decision in his team*.

According to Van der Wal and Van der Maas ninety times a year the life of a severely handicapped newborn is terminated.⁶ According to the report 'To act or to Abstain' annually a dozen newborn babies die due to termination of life because of abstention or no further medical treatment.⁷ As a result of the Prins and Kadijk case law and the 1996 discussion group advice, from 1998 until 2002 Dutch physicians reported fifteen cases of deliberate termination of

³ Rb Alkmaar 26 April 1995, *TvGR* 1995/41 and Hof Amsterdam 7 November 1995, *TvGR* 1996/1.

⁴ Rb Groningen 13 November 1995, *TvGR* 1996/2 and Hof Leeuwarden 4 April 1996, *TvGR* 1996/5. See for a translation in English J. Griffiths et al., *Euthanasia & law in the Netherlands*, Amsterdam: Amsterdam university press 1998, p. 341.

⁵ *Toetsing als spiegel van de medische praktijk*, Rapport van de overleggroep toetsing zorgvuldig medisch handelen rond het levenseinde (Assessment as mirror of medical practice, containing an English summary), Ministerie van volksgezondheid, welzijn en sport, 1996.

⁶ G. van der Wal en P.J. van der Maas, *Euthanasie en andere medische beslissingen rond het levenseinde* (Euthanasia and other medical decisions at the end of life), Den Haag: Sdu uitgeverij 1996, p. 181-201.

⁷ *Doen of laten* (To act or to Abstain?), p. 20.

a newborns life to the Board of Prosecutors General.⁸ In all fifteen cases the physician was not prosecuted.

The restricted number of cases notified was related to two major objections against the existing notification procedure:

- the assessment of the termination of life was made mainly from the criminal law point of view, and
- the consequences of the notification for the doctor who took the end of life decision were still uncertain.⁹

In the meantime a group of paediatricians in the academic hospital of Groningen (Beatrix children's hospital) elaborated a medical protocol for dealing with problems of severely handicapped newborns (the Groninger protocol).¹⁰ The protocol gives guidelines to the medical team of the severely handicapped child about how to make decisions. The team exist of a gynaecologist, a paediatrician, nurses and others who give medical care to the child. The protocol is in fact a further elaboration of the criteria for due care as ruled in the Kadijk decision. The protocol emphasizes that one physician should have the final responsibility for the termination of the life of a severely handicapped newborn. This decision shall be carefully taken after consultation with the team and the parents. According to the protocol the responsible doctor shall report the termination of the life to the coroner. The aim of the protocol is to make termination of the life of newborns transparent.

The initiators of the Groningen protocol claimed in 2004 to establish an advising committee for the active termination of the life of severely handicapped newborns. This committee should, unlike the euthanasia committee that gives a final decision on the accuracy of euthanasia, give an opinion to the public prosecutor how to proceed with the notification.¹¹ Finally the public prosecutor should decide whether to prosecute or not.

⁸ J.H.H.M. Dorscheidt and A.A.E Verhagen, *Een centrale toetsingcommissie voor beslissingen rond het levenseinde bij pasgeborenen: een brug te ver* (A central assessment committee for decisions on the end of life of newborn babies: a bridge too far), *NJB* 2004, p. 2141-2147.

⁹ Dorscheidt/Verhagen, *op.cit.*, p. 2143.

¹⁰ The Groninger protocol has not been made public and is only available for gynaecologists and paediatricians. We got a copy through contacts in medical circles.

¹¹ Dorscheidt/Verhagen, *op.cit.*, p. 2141-2147 and W.L.J.M. Duijst, *Boeven in het ziekenhuis, Een juridische beschouwing over de verhouding tussen het medisch beroepsgeheim en de opsporing van strafbare feiten* (Criminals in the hospital, A judicial reflection on the relation between medical confidentiality and the investigation of crime), Den Haag: Sdu uitgevers, 2005, p. 141.

In the meantime that the problems of severely handicapped newborns became more transparent, a serious discussion on palliative sedation was held, which resulted in the 2005 guidelines on palliative sedation.¹²

The uncertainty of doctors how to react in cases of severely physically defect fetuses or newborn children forced the Deputy Minister of Health and the Justice Minister to issue, in response to the report 'Medical decisions at the end of life',¹³ a proposal for an assessment procedure and criteria of due care in order to create certainty for doctors on how to proceed in these cases. The proposal, laid down in a letter to Parliament, deals with the various situations that have been elaborated at the beginning of this article.

In order to avoid undue criminal proceedings against doctors in cases of termination of life on severely defect babies which according to the letter of the law might constitute the crime of murder, a new procedure of notification has been developed. Under the new procedure the coroner will send the form to a national committee of experts consisting of five members: a chairman, who is a lawyer, three medical specialists and a specialist in medical ethics. The three medical specialists have a specialisation as neonatologist, paediatric child neurologist or gynaecologist.¹⁴ This committee decides on whether the doctor has performed in conformity with the criteria of due care. The opinion of the committee will be sent to the Board of Prosecutors General and is taken into consideration for its prosecutorial decision. This means that the decision to prosecute or to waive prosecution is not only based on legal prosecutorial views but also on medical and ethical views.

Criteria of due care

In the proposal criteria of due care for termination of life of a newborn baby and criteria of due care for late induced abortion are formulated.

In case of a termination of life of a severely defect newborn baby the doctor has performed carefully when:

- a) according to medical insights it is doubtless that there exists unbearable suffering and that there is no prospect of improvement, so that it is justified to refrain from medical treatment;
- b) the parents agree with the termination of life;
- c) the parents have been carefully informed by the doctor on the diagnosis and prognosis; both he and the parents must have reached the conclusion that there is no reasonable alternative;

¹² Commissie landelijke richtlijn palliatieve sedatie, KNMG richtlijn palliatieve sedatie, 2005.

¹³ TK 2005-2006, 30300 XVI, no. 90 (Hansard 2005-2006, no. 30300 XVI, p. 1-8).

¹⁴ In case of a late induced abortion.

- d) he has consulted at least one other physician who must have seen the baby and who has achieved an independent opinion on the conformity with the criteria of due care; this opinion must be given in writing; and
- e) the life has been terminated with due medical care.

The criteria of due care for late induced abortion are similar to the criteria for the termination of life as far as it concerns criteria c, d and e. The other criteria are more or less similar to the criteria for the termination of life. The most important criterion is that the defect must be such that after the delivery medical treatment will be refrained from due to the medical opinion that medical treatment is useless. There may be no doubt at all about the diagnosis and prognosis. A continuation of the pregnancy according to actual medical insight is unlikely to contribute to a more accurate diagnosis. The mother has to make a request for the induced abortion.

Some critical remarks

We want to make some critical remarks about the assessment procedure.

The criterion that the parents have to agree with the decision, implicates that the doctor (with his team) takes a decision and the parents have to agree. This is unlike the procedure in euthanasia in which the patient has to make a request. And it is unlike the procedure in palliative sedation, in which consensus has to exist between the doctor and the patient, or when the patient is not able anymore to communicate, between the doctor and the patient's family. In case of euthanasia or palliative sedation the initiative is more with the patient than with the doctor. To make the right decision on a newborn's life in our opinion true and complete consensus is necessary and not merely agreement by the parents.

The criterion, that it should be *doubtless* that *unbearable suffering* is present, bears a double problem. Only after delivery it is possible to determine that there is no doubt at all that a child is severely handicapped. Before delivery there can only be a (very high) suspicion that the child will be handicapped. Occasionally there are reports of foetuses that are expected to be severely handicapped but who appear to be perfectly healthy once they are born.¹⁵

It is just as difficult to determine that a child is unbearable suffering as it is to be sure about the handicap. Many Dutch doctors believe that unbearable

¹⁵ Statement partly based on my own experience as GP (WD).

suffering cannot be determined in people who are not able to communicate.¹⁶ Furthermore the suffering can be treated by means of palliative sedation.¹⁷

The last critical remark is about one of the criterion in case of induced abortion. The mother has to make a request. This implicates that the abortion can be done on the mothers initiative. The criterion completely rules out the father of child. This is inconsistent because when the child is viable (after more than 24 weeks pregnancy) and has a very poor prognosis and the delivery would be awaited, the father's opinion would be of importance. So in our opinion the father should be able to clarify his point of view on induced abortion after more than 24 weeks pregnancy.

Prosecutorial decision making

On March 15th 2007 the above mentioned proposal by the Deputy Minister of Health and Minister of Justice was elaborated and laid down in a Ministerial Regulation that came into force establishing a national committee of experts which task it is to assess whether the doctor has performed an end of life decision on severely handicapped fetuses or newborn in conformity with due care criteria. The opinion of the committee has to be send to the Board of Prosecutors General which will take that opinion into consideration for its prosecutorial decision. Also in March 2007 the Board of Prosecutors General issued an extensive direction on how the prosecution service will proceed in cases of termination of life without explicit request and late termination of pregnancy¹⁸, in other words, on what circumstances the prosecution service as a rule will prosecute and on what circumstances the prosecution service is likely to waive a case and not take further action. The directive deals with three various cases of termination of life without explicit request:

Case 1: Termination of life without request (in relation to persons incompetent to express their will, but not including unbearable suffering newborns)

Sometimes termination of life is performed on someone who is not competent to request for euthanasia, such as juveniles under the age of twelve, unconscious patients or demented patients who did not sign a previous will. In this case there is no request and the Euthanasia Act is not applicable. The coroner has to notify the public prosecutor who has to decide whether or not the act of the doctor is justified due to necessity. He will receive a report by the coroner on the cause of death. The prosecutor may investigate the case and

¹⁶ M.M. Beijl, Ondraaglijk lijden (Unbearable suffering), *Medisch Contact* 1998, p. 825-827. T.H.R. de Jong c.s., Laten sterven of doen sterven (To abstain or to terminate life), *Medisch contact* 2006, p. 699-671.

¹⁷ De Jong c.s., Laten sterven of doen sterven (To abstain or to terminate life), *Medisch contact* 2006, p. 699-671.

¹⁸ Staatscourant 6 maart 2007, no. 46, p. 10.

ask the opinion from the Health Inspector and shall send a proposal for further decision making to the Board of Prosecutors General. The Board as well may ask for a judicial investigation by the examining judge before a final decision on (non-)prosecution is taken. For a (non-)prosecution consent by the Minister of Justice is always required.

Case 2: Termination of life of newborns

In case of a termination of life of a newborn the coroner shall send the notification and his report on the cause of death directly to the national committee of experts. This committee will assess whether or not the doctor performed a termination of life in conformity with the criteria of due care and shall send its opinion to the Board of Prosecutors General. When necessary the Board will ask for a judicial investigation by the examining judge before a final decision on (non-)prosecution is taken. For all prosecution decisions – the decision to prosecute or to waive the prosecution – prior consent by the Minister of Justice is required.

The Board informs the national committee of experts. In case the national committee came to the conclusion that the doctor did not meet the criteria of due care or in case the Board decided to prosecute, the Chief Health Inspector is informed as well.

The directive rules that a prosecution is indicated when it is not beyond doubt that there exist unbearable suffering and no prospect of improvement.

When the parents did not agree with the termination of life, prosecution as a rule will take place as well provided that the consultation with the parents was not fully appropriate.

One of the criteria of due care is that the doctor who performs a termination of life on a severely handicapped newborn has to consult at least one other physician who must have seen the baby and who has achieved an independent opinion on the conformity with the criteria of due care.

This criteria may cause problems because in many hospitals it is practice that a case of termination of life of a severely handicapped baby is performed only after prior consultation of a multidisciplinary team which discusses the present and future health state of the baby, the prognosis of further suffering, the life expectancy, the treatment perspectives, etc.

The mere fact that the requirement on consultation of another physician has not been met is, according to the directive, not a reason to prosecute provided that otherwise a clear picture of the medical state of the baby could have been achieved as far as it concerns the unbearable suffering and the lack of prospects of improvement of the medical state of the baby.

Non-compliance with the criteria that life has been terminated with due medical care is not an obstacle for a defence on necessity. Therefore prose-

cutation in such a case is as a rule not indicated. Such a case, however, should lead to action against the doctor by the Health Inspectorate.

Case 3: Late termination of pregnancy

In relation to the late termination of pregnancy the directive deals with the two different categories as we discussed at the beginning of this chapter:

- 1) the situation that the foetus' ailment is such that it can medically be assumed that the foetus will die immediately during or shortly after the delivery, and
- 2) the situation that the physical defects will cause serious and irreparable dysfunction but nevertheless a life expectancy – though restricted – exists.

As we have seen supra a termination of pregnancy in a situation mentioned under 1) does not constitute a criminal offence due to the justification ground of sect. 296, subsect. 5, PC if the rules for induced abortion laid down in the Termination of Pregnancy Act are complied with. A termination of pregnancy in a situation mentioned under 2) falls within the scope of sect. 82a PC and constitutes a crime which, however, may be justified due to necessity (sect. 40 PC).

In both situations the doctor who performs a late termination of pregnancy is statutorily obliged to notify the coroner because in neither case a natural death occurred. The coroner in the situation under 1) has to notify the public prosecutor and to send him his opinion on the late termination of pregnancy. In the situation under 2) the coroner has to notify the national committee of experts.

In the situation under 1) the public prosecutor sends his opinion on the case to the Board of Prosecutors General which as a rule will take no further action (waive-prosecution). No prior consent by the Minister of Justice is required.

In very exceptional cases, further investigation by an examining judge may be indicated or the national committee of experts may be asked to give its opinion before the Board of Prosecutors General will take their decision.

In a situation under 2) the national committee of experts will assess whether or not the doctor performed a late termination of pregnancy in conformity with the criteria of due care. The opinion of this committee will be used by the prosecution service for its decision to prosecute or to waive prosecution.

The Board of Prosecutors General informs the national committee of experts on its prosecution decision. The Board informs the Chief Health Inspector in all cases the national committee came to the conclusion that the physician did not comply with the criteria of due care and in cases the Board decided to prosecute the doctor.

Prosecution decisions:

- in situations mentioned under 1): as a rule in such situations prosecution cannot take place because late termination of pregnancy does not fall within the scope of sect. 82a PC and therefore does not constitute an offence. When, however, doubts exist whether an ailment is such that it can medically be assumed that the foetus will die during or shortly after the delivery and in fact a situation mentioned under 2) is present, the prosecution service will ask the national committee of experts advice and take its decision on the basis of this advice.

- in situations mentioned under 2): prosecution as a rule is indicated when an ailment does not lead to a situation mentioned under 2) or when there does not exist an actual or foreseeable unbearable suffering without prospects of improvement.

A prosecution is as well indicated when there is no explicit request by the mother. The absence of a request by the mother is as a rule an indication that the communication between the doctor and the parents and the information on the diagnosis and prognosis was inappropriate.

A non-compliance with the due care criteria that an independent other physician has to be consulted will not lead to a prosecution when the decision for a late termination of pregnancy is the result of a prior consultation process with a multidisciplinary team.

Non-compliance with the criteria that a late termination of pregnancy has to be performed with due medical care will not lead to prosecution but will be reported to the Health Inspectorate in order to consider further actions against the doctor.

The directive of the Board of Prosecutors General is the keystone in the regulation on end of life decisions on severely handicapped fetuses and newborns in the Netherlands. The directive makes clear that doctors who perform these end of life decisions do not risk a prosecution provided that they comply with all criteria of due care as laid down in the ministerial regulation on the establishment of the national committee of experts.

The directive of the Board clearly formulates the prosecution policy in relation to end of life decisions without explicit request. It shows that prosecutorial decisions in these cases are not merely based on legal prosecutorial views but also on medical and ethical views, because when a prosecutorial decision has to be taken prior consultation with the national committee of experts will be the rule. On the one hand this can be considered as a safeguard for the physicians and medical specialists because prosecutorial decisions are not pure juridical but also medical based. On the other hand prior consultation with the national committee of experts means that the highest standards and the most recent standards of due medical and ethical care have to

be complied with. Vulnerable persons – fetuses, newborns and incompetent persons – deserve these highest standards.