Euthanasia and physician assisted suicide in the Netherlands

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The Netherlands

The context of euthanasia and physician assisted suicide in the Netherlands is one within the quality domains of palliative care

Palliative care team

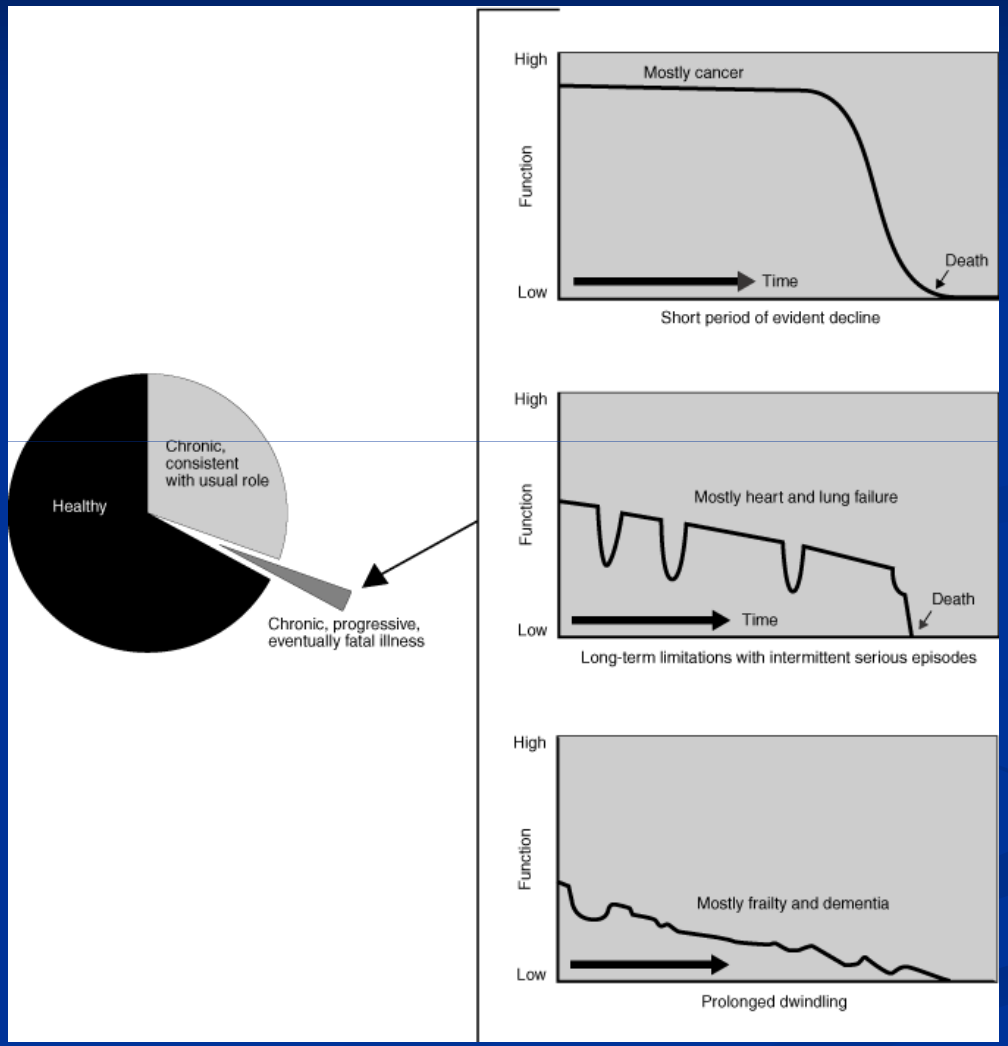
José, Josien, Jolanda, Patricia, Joep

Sake, Gert-Jan, Jacques, Caro

Multidisciplinary hospital palliative care team (in-patient, out-patient)

Joep, Theo, Annemieke, Martin

Palliative care in hospitals



⟸ Cancer

⟸ Heart -and lung diseases

⟸ Frail elderly, dementia

Team quality consultation domains

- Structures and processes of care
- Physical aspects of care
- Psychological and psychiatric aspects of care
- Social aspects of care

National Consensus Project for Quality Palliative Care

Team quality consultation domains

- Spiritual, religious and existential aspects of care
- Cultural aspects of care
- Care of the imminently dying patient
- *Ethical and legal aspects of care*
- Loss, grief and bereavement aspects of care

NATIONAL CONSENSUS PROJECT FOR QUALITY PALLIATIVE CARE

Phases of disease and illness

Disease modifying treatment

Death

Time

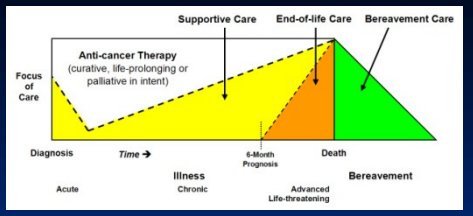
Diagnosis - e.g. bad news

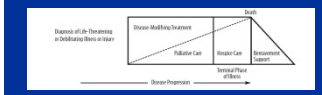
Loss, grief and bereavement

The last 24-72 hours

Early integration of palliative care domains into disease modifying treatment

From tumor-orientation to symptom-orientation





Euthanasia (E) and physician assisted suicide (PAS) in the Netherlands

Henk Landa (65 yrs) case history

Patient and family permission to show photographs

Medical history: summary (1/4)

- Diagnosis: *carcinoma of the oesophagus* (mid-thoracic) with at presentation metastases of the mediastinal lymph nodes, lungs and liver (stage 4)

- Course: *transition to palliative care* with on Henk's request no invasive procedures
  such as laser treatment, brachytherapy
  and e.g. palliative chemotherapy

Medical history: summary (2/4)

- Physical symptoms:

- ✓ Dysphagia (stricture)
- ✓ *Regurgitation (food) with sialorrhea*
- ✓ Anorexia and cachexia (CACS)
- ✓ Retrosternal pain
- ✓ *Dyspnoea and productive cough* (aspiration)
- ✓ Hoarseness (laryngeal nerve involvement)
- ✓ Weakness

Medical history: summary (3/4)

- Psychological symptoms:

✓ *Anxiety to suffocate* (massive aspiration)

Medical history: summary (4/4)

- Level of independence: functionality

- ✓ Detoriation of condition with progressive (unbearable) symptom distress, including anxiety to suffocate

- ✓ Complete dependent on others (bedridden)

- ✓ *Development not fitting with patient's personhood*

Patient and family: summary (1/2)

- Married with Alie (65 yrs) for more then 40 yrs
- 4 (married) children (26, 28, 30 and 35 yrs)
- Grandfather and grandmother of 8 grandchildren
- *Sound family dynamics and coalitions*

Patient and family: summary (2/2)

- Patient:

✓ Succesful entrepreneur

✓ *High level of independence* (autonomy, decision making)

✓ Family man

✓ Marathon runner

The termination of life request

- *Voluntary request in writing* after due consideration, including results of several family meetings (other)
- *High level of request stability over time*
- After *life review* satisfied with the life already lived
- In a process of *closure of life affairs*

Unbearable suffering

- Unbearable suffering devoid of any hope (improvement)

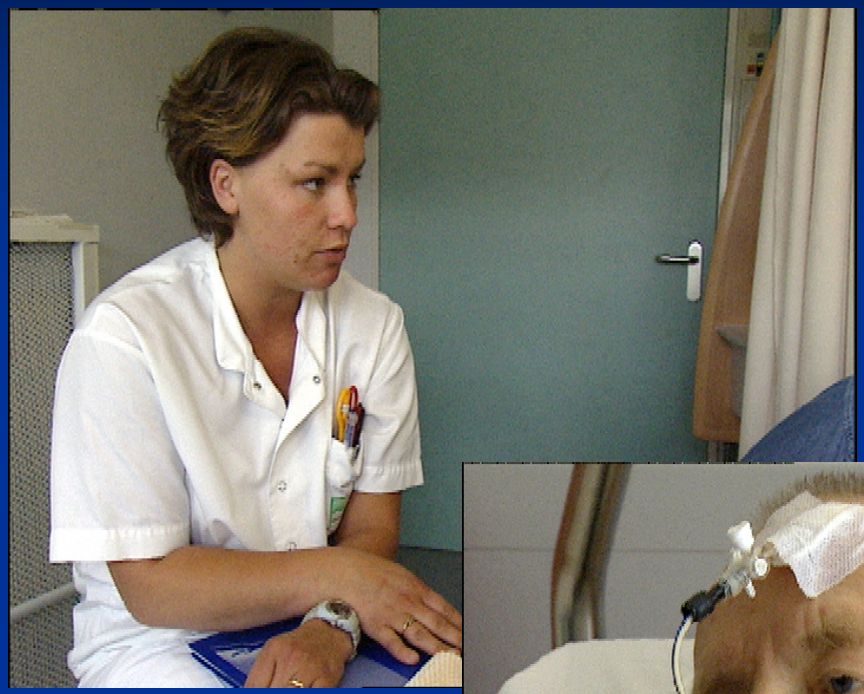
- ✓ High level of (symptom) distress, including anxiety to suffocate

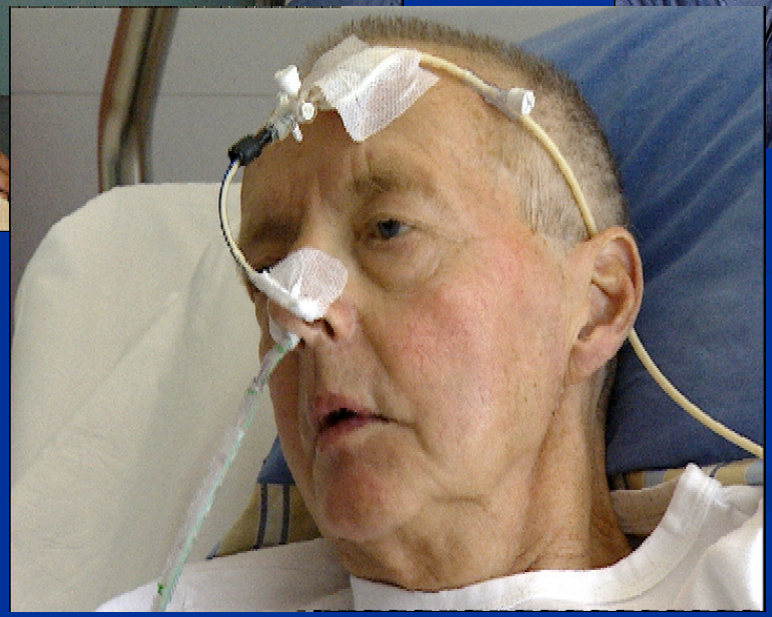
- ✓ Complete dependent on others (bedridden)

- ✓ Not fitting with personhood (autonomy, decision making, human dignity)

Outcome SOS V device high

Feelings and emotions





Role of physician and nurses: *A,B,C and D of dignity conserving care*

The *ABCD of dignity conserving care* at the EOL

- A = Attitude
- B = Behaviour
- C = Compassion
- D = Dialogue

Healthcare providers have a profound influence on how patients experience illness and on their sense of dignity

Chochinov HM, The A, B, C and D of dignity conserving care, BMJ 2007

The consultation

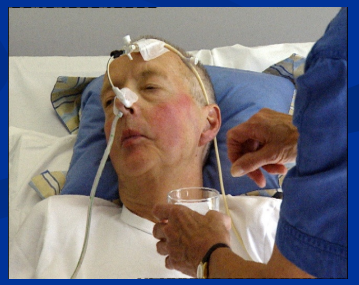
- Formal (SCEN) *independent consultation* (physician) in accordance with request and unbearable suffering

- (SCEN project = Support Consultation Euthanasia [and Physician Assisted Suicide] the Netherlands)

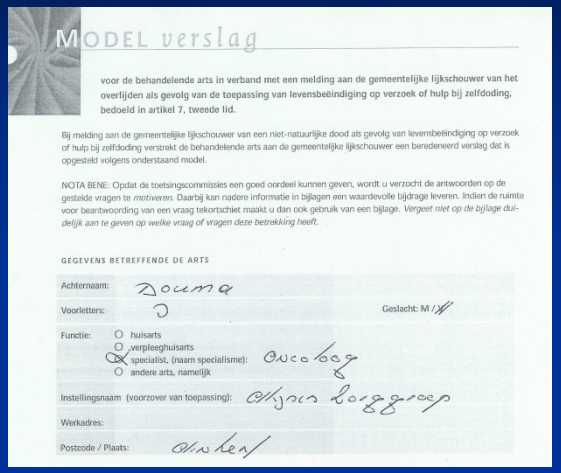
E / PAS

- *Induction of coma* with 1500mg Thiopental sodium (Nesdonal) i.v. / 10 minutes

- *Induction of muscle relaxation* with 20mg Pancuroniumdibromide (Pavulon) i.v. / 10 minutes



Review board E / PAS: due care



MODEL verslag

voor de behandelende arts in verband met een melding aan de gemeentelijke lijkschouwer van het overlijden als gevolg van de toepassing van levensbeëindiging op verzoek of hulp bij zelfdoding, bedoeld in artikel 7, tweede lid.

Bij melding aan de gemeentelijke lijkschouwer van een niet-natuurlijke dood als gevolg van levensbeëindiging op verzoek of hulp bij zelfdoding verstrekt de behandelende arts aan de gemeentelijke lijkschouwer een beredeneerd verslag dat is opgesteld volgens onderstaand model.

NOTA BENE: Opdat de toetsingscommissies een goed oordeel kunnen geven, wordt u verzocht de antwoorden op de gestelde vragen te *motiveren*. Daarbij kan nadere informatie in bijlagen een waardevolle bijdrage leveren. Indien de ruimte voor beantwoording van een vraag tekortschiet maakt u dan ook gebruik van een bijlage. *Vergeet niet op de bijlage duidelijk aan te geven op welke vraag of vragen deze betrekking heeft.*

GEGEVENS BETREFFENDE DE ARTS

Achternaam: Douma

Voorletters: D Geslacht: M / V

Functie: ○ huisarts ○ verpleeghuisarts ☒ specialist, (naam specialisme): oncoloog ○ andere arts, namelijk

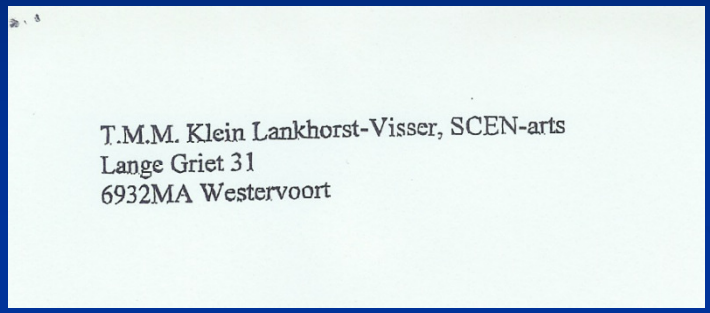
Instellingsnaam (voorzover van toepassing): Atrium Leeggroep

Werkadres:

Postcode / Plaats: Alnken

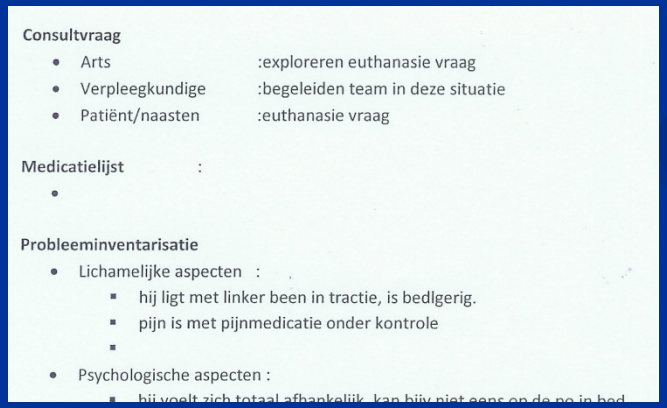
Special form independent physician (SCEN)

Special form E / PAS



T.M.M. Klein Lankhorst-Visser, SCEN-arts
Lange Griet 31
6932MA Westervoort

Special form palliative care team



Consultvraag

- Arts :exploreren euthanasie vraag
- Verpleegkundige :begeleiden team in deze situatie
- Patiënt/naasten :euthanasie vraag

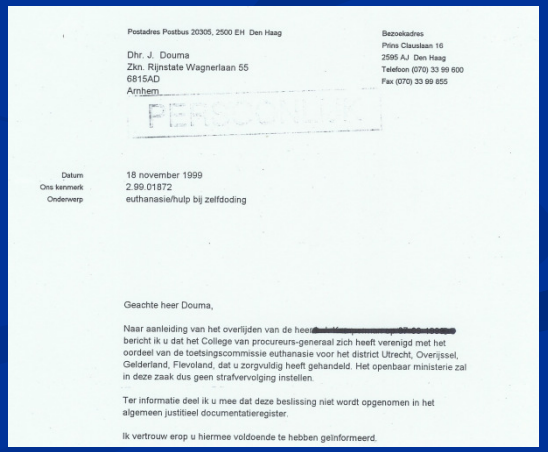
Medicatielijst :

-

Probleeminventarisatie

- Lichamelijke aspecten :
  - hij ligt met linker been in tractie, is bedlgerig.
  - pijn is met pijnmedicatie onder kontrole
  -
- Psychologische aspecten :
  - hij voelt zich totaal afhankelijk, kan hijv niet eens op de no in bed

Due care report



Postadres Postbus 20305, 2500 EH Den Haag

Bezoekadres
Prins Clauslaan 16
2595 AJ Den Haag
Telefoon (070) 33 99 600
Fax (070) 33 99 855

Dhr. J. Douma
Zkn. Rijnstate Wagnerlaan 55
6815AD
Arnhem

FERSCHRIJVEN

Datum 18 november 1999
Ons kenmerk 2.99.01872
Onderwerp euthanasie/hulp bij zelfdoding

Geachte heer Douma,

Naar aanleiding van het overlijden van de heer [redacted] bericht ik u dat het College van procureurs-generaal zich heeft verenigd met het oordeel van de toetsingscommissie euthanasie voor het district Utrecht, Overijssel, Gelderland, Flevoland, dat u zorgvuldig heeft gehandeld. Het openbaar ministerie zal in deze zaak dus geen strafvervolging instellen.

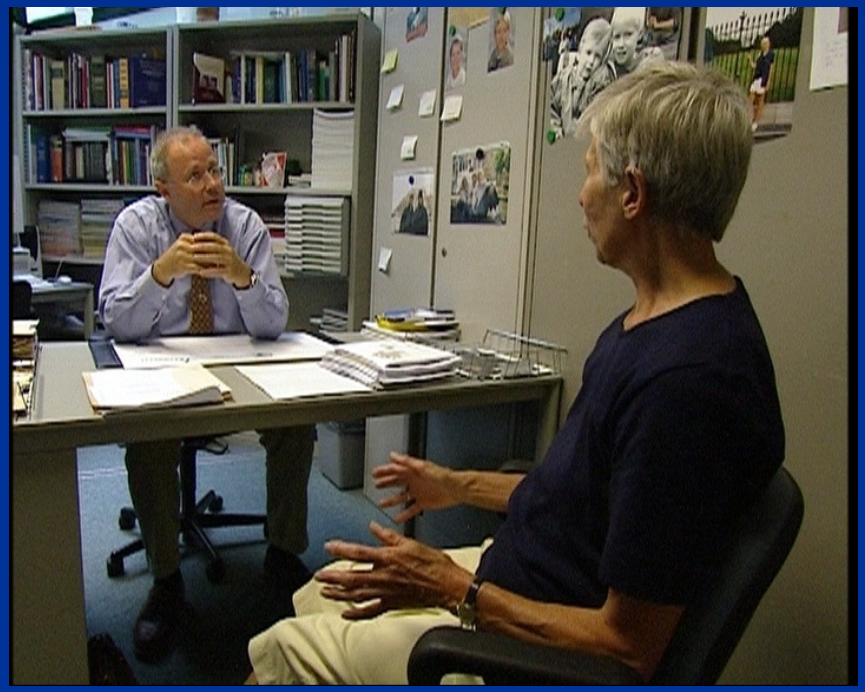
Ter informatie deel ik u mee dat deze beslissing niet wordt opgenomen in het algemeen justitieel documentatieregister.

Ik vertrouw erop u hiermee voldoende te hebben geïnformeerd.

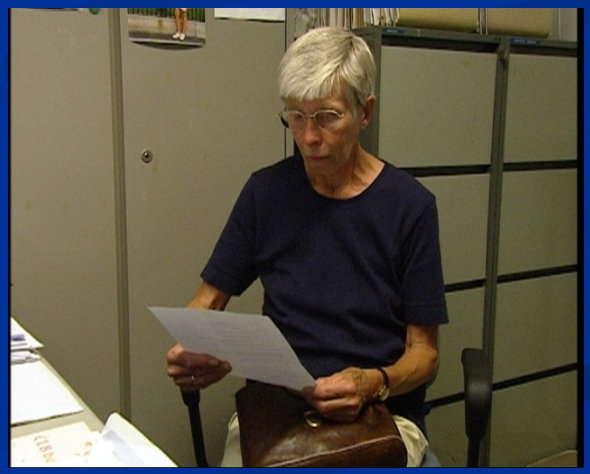
Living will

In twee weken bedrust kan veel gebeuren: het had gekund dat ik na verloop van tijd vrede zou kunnen krijgen met mijn huidige situatie. Dit is echter niet gebeurd: ondanks veel positieve aandacht (bezoeken van familie, vrienden, collega's) blijft het verlies van mijn onafhankelijkheid een groot verdriet voor mij. De afhankelijkheid die ik nu heb is voor mij erger dan ik had kunnen denken: hoewel ik zo veel mogelijk zelf probeer te doen, zijn er zaken waar ik wel hulp voor moet vragen (ontlasting etc.). Maar los daarvan verplichte de simpelste zaken mij om te bellen om hulp: als ik een potlood van kastje stoot moet ik al de verpleging om hulp vragen.

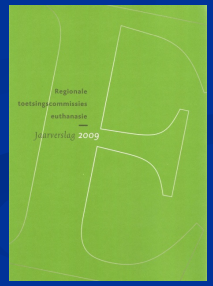
Closure

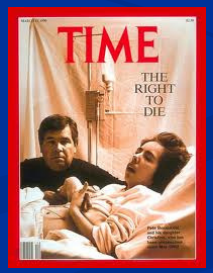


Trajectory of follow-up care after 6 weeks

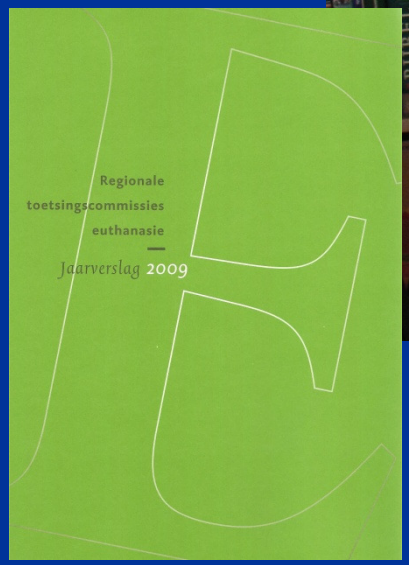


Inside the review board





Inside information from the review board euthanasia / physician assisted suicide (physician, ethicist and lawyer)



Annual report
2009

Content

- Statistical data
- Starting points for review
- Special points of interest
- Observations
- Procedure euthanasia review board (optional)

Content

- Statistical data
- Starting points for review
- Special points of interest
- Observations
- Procedure euthanasia review board (optional)

Statistical data (1/5)

Year	Number
1999	2216
≈	≈
2003	1815
≈	≈
2007	2120 (*willingness to report almost 100%*)
≈	≈
2009	2636

Source: Annual reports review board E / PAS the Netherlands

Statistical data (2/5)

E vs PAS vs combination	Number	%
E	2443 / 2636	*92,7*
PAS	156 / 2636	5,9
Combination	37 / 2636	1,4

Source: Annual report 2009 review board E / PAS the Netherlands

Statistical data (3/5)

Disease / year	1999	≈	2009
Cancer	*90,3 %*	≈	*81,7 %*
Diseases of the nervous system	2,3 %	≈	5,0 %
Diseases of the lung	2,3 %	≈	5,5 %
Cardiovascular diseases	1,6 %	≈	2,0 %
AIDS	0,3 %	≈	0,2 %
Other diseases	3,2 %	≈	5,6 %

Source: Annual report 1999 / 2009 review board E / PAS the Netherlands

Statistical data (4/5)

Year / physician	*General physician*	Specialist	Nursing home physician	Other disciplines
1999	*1875/84,6 %*	296/13,4 %	44/2,0 %	1/-
≈	≈	≈	≈	≈
2009	*2117 / 80,3 %*	170 / 6,5 %	188 / 7,1 %	6,1 % (*hospice 4,7 %*)

Source: Annual report 1999 / 2009 review board E / PAS the Netherlands

Statistical data (5/5)

2005: EOL decision making	Number	%
E / PAS / combination	1933 / 136.000	*1,4*
PS KNMG guideline palliative sedation 2005	11.150 / 136.000	*8,2*

Several Dutch government reports / 5-yr surveys death register

Summary

- Mainly used in patients with cancer (≈85%)
- More or less the domain of the general physician (≈80%)
- Willingness to report almost complete (≈95%)
- *Figures (annual cases) show increase over time*
- E (≈90%) outrange PAS
- E / PAS 1,4% of EOL decision making (2005)

Content

- Statistical data
- Starting points for review
- Special points of interest
- Observations
- Procedure euthanasia review board (optional)

Starting points for review *afterwards*

- Unbearable suffering devoid of any hope
- Voluntary request after due consideration
- Consultation
- The action (execution)
- Conclusion
- Scope for personal comments review board

Formal opinion euthanasia / physician assisted suicide review board

- Procedure (law)
- Facts and circumstances
- ✓ Nature of (unbearable) suffering, (level of) information provision and (discussed) alternatives
- ✓ (Stability) of termination of life request
- ✓ (Independent) consultation (level of concordance)
- ✓ The action (execution)
- Review (summary)
- Decision

Due care requirements to be examined and / or taken into account by the physician

- A voluntary request after due consideration, preferably of a lasting nature (request stability)
- Long-lasting, unbearable suffering devoid of any hope (perspective)

Due care requirements to be examined and / or taken into account by the physician

- Prior consultation with an independent (experienced) physician
- Proper reporting

Due care requirements to be examined and / or taken into account by the physician

- Consulting other care providers (e.g. nurses) involved in the case
- Preventing unnecessary suffering among the family (and friends)

Due care requirements to be examined and / or taken into account by the physician

- The physician is present and / or can be reached (PAS)
- Acting with due care from a medical-technical perspective

Content

- Statistical data
- Starting points for review
- Special points of interest
- Observations
- Procedure euthanasia review board (optional)

A voluntary *request* after due consideration, preferably of a lasting nature

- Explicit and specific request by the patient him / herself, preferably in writing
- No room for assumed permission
- Attention for communication, information and determining a patient's living will (advance directives)

Long-lasting, *unbearable suffering* devoid of any hope

- Thé requirement of due care is at the center of the debate on euthanasia / physician assisted suicide
- Attention is paid to subjectivity, objectivity and the real treatment prospects of the suffering, both somatic and / or psychological (e.g. SOS V device)
- Knowledge, attitude and skills regarding palliative care

Review board E / PAS results 13-08-2008 (33 cases)

Report number	Medical signs and symptoms	Loss of function	Personal aspects: self-appraisal, loss of independence	Aspects of social environment	Total number
242;244;246;251; 256;257;258;259; 260;265	+				10
233;234;238;241; 243;254;261;266	+		+		8
235;239;245;248; 252;253	+	+			6
236;237;255;263	+	+	+		4
249;250;264			+		3
240	+		+	+	1
262					Not evaluable

Source: Joep Douma (E / PAS review board) SOS V evaluation

Prior consultation with an independent physician

- Independent with respect to patient, close relatives and attending physician
- A counselor with expertise in this field (SCEN project: Support and Consultation in case of Euthanasia and assisted suicide in the Netherlands)
- Attention is paid to divided consultation, differences of opinion and reporting

Reporting

- Obligation to keep a file in accordance with the Medial Treatment Agreement Act
- Reporting must provide detailed information on the existing requirements of due care
- Reporting must form a basis for accountability

Consulting other care providers involved in the case

- In general of special significance in the stage when views are formed
- Useful and desirable within the context of putting together a comprehensive file
- Care providers keeping a file of their own may be useful

Preventing unnecessary suffering among the family

- Striving towards consensus of feelings
- The patient's right to privacy prevails
- Attention is paid to the follow-up interview

Acting with due care from a medical-technical perspective and a physician who is present / can be reached

- KNMP euthanatica guideline (Dutch society of pharmacists)
- Consultation with pharmacist desirable
- Special attention paid to assisted suicide (presence / ability to be reached)

Content

- Statistical data
- Starting points for review
- Special points of interest
- Observations
- Procedure euthanasia review board (optional)

Observations regarding review of due care requirements

- Overtime request stability sometimes unclear
- Extent of suffering is sometimes difficult to assess
- Quality of palliative care applied not always clear (e.g. communication skills, dealing with emotions, shared-decision-making, health care ethics [consultation])

Observations regarding review of due care requirements

- Consultation is not always convincing. SCEN project stands for a major improvement (Support and Consultation in case of Euthanasia and physician assisted suicide in the Netherlands)

- Sometimes keeping a file leaves something to be desired (reporting)

Observations regarding review of due care requirements

- The action (execution) not very consistent
- Extent to which physician can be reached (assisted suicide) not always well organized
- Trajectory surrounding follow-up care (e.g. family, friends and caregivers) unknown (no obligation)

Practical information and points of interest / the action (execution)

- Induction of coma with Thiopental sodium (Nesdonal) 20mg/kg in NaCl 0.9% i.v. (1-2g)

- Induction of muscle relaxation with Pancuroniumdibromide (Pavulon) 0.3mg/kg in NaCl 0.9% i.v. (16-24mg)

Practical information and points of interest / the action (execution)

- Mixtura nontherapeutica pentobarbitali 9g/100ml (liquid)

Formal opinion euthanasia / physician assisted suicide review board

- Procedure (law)
- Facts and circumstances
- ✓ Nature of (unbearable) suffering, (level of) information provision and (discussed) alternatives
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- ✓ The action (execution)
- Review (summary)
- Decision

Palliative sedation *versus* E / PAS

	Palliative sedation	*Euthanasia / PAS*
Aim	Treatment of refractory symptoms, lowering consciousness	Death
Decision process	Consensus (caregiver) [not always possible, emergency], no second opinion, no board review	Request (patient) [consensus], unbearable suffering, second opinion, carrying out, board review
Shortening of life	No	Yes
Reversible	Yes	No
Drug(s)	Midazolam Levomepromazine	Thiopental sodium Pancuroniumdibromide Mixtura pentobarbitali
Dosage(s)	NA	NA
Administering	Preferably subcutaneous, pump	Intravenous, orally

Thank you for your attention

José, Josien, Jolanda, Patricia, Joep

Sake, Gert-Jan, Jacques, Caro

Multidisciplinary hospital palliative care team (in-patient, out-patient)

Joep, Theo, Annemieke, Martin