BELGIAN ADVISORY COMMITTEE ON
Bioethics

Opinion no. 73 of 11 September 2017 on euthanasia in case of non-terminally ill patients, psychological suffering and psychiatric disorders

CONTENT OF THE OPINION

A. Request for an opinion

The request for an opinion from Mrs L. Onkelinx, then Minister for Health and Social Affairs, by letter dd. 14 April 2011 with as reference "Euthanasia for non-terminally ill patients" in turn refers to an oral question Senator Elke Sleurs had asked in the wake of the mediatised case of a couple who had sought and obtained permission for euthanasia. In the context of a request for euthanasia from a couple where one of the partners was not terminally ill, Senator Elke Sleurs enquired about the legal basis to obtain euthanasia in cases where the applicant is not terminally ill. To quote Senator Elke Sleurs: "If the legal basis for euthanasia for a non-terminally ill patient whose partner already obtained permission for euthanasia among other matters includes ‘unbearable psychological suffering’, do you believe that there is a societal need to clarify this concept?".

It is essential to shed light on the principles that are raised by this question, with the specification however that it is not up to the Committee to comment on a case that was highlighted in the media and of which the exact details, more specifically the medical condition of both partners, are unknown.

The members of the Committee distinguish between the following three questions: the first two questions will be dealt with concisely; the third question forms the essence of the ethical debate in this Opinion.

Question 1: Does the legal basis to obtain euthanasia vary in cases where also the partner’s request for euthanasia can be granted?

Question 2: What is the legal basis to obtain euthanasia if the applicant is not terminally ill?

Question 3: Is there a societal need to clarify the concept of constant and unbearable psychological suffering that cannot be alleviated, resulting from a serious and incurable disorder caused by accident or illness?

Before addressing the three questions raised by the request for an opinion, we will start by briefly outlining the Belgian legal framework for euthanasia.

B. Legal framework for the decriminalisation of euthanasia in Belgium

B.1. General framework

The Belgian Euthanasia Act of 28 May 2002 (hereinafter the Euthanasia Act) makes it possible for every legally competent, conscious adult[1] patient to voluntarily, in a well-considered manner and repeatedly ask for euthanasia if he/she finds himself/herself in a medically hopeless condition experiencing constant and unbearable physical or psychological suffering, resulting from a serious and incurable disorder caused by accident or illness, that cannot be alleviated.

This effectively removes the act of euthanasia from the penal sphere (i.e. the Act decriminalises the act of euthanasia), under stringent conditions, and describes the procedure any physician who receives such requests must adhere to.

The Euthanasia Act exhibits mixed characteristics: it forms part of civil law, under the chapter medical law, but also has aspects that pertain to criminal law since it no longer criminalises the act of euthanasia, performed by a physician, in accordance with the statutory conditions and procedures.

The argument for decriminalising euthanasia is usually made on the basis of two ethical principles: respect for the patient’s autonomy and empathy with his/her suffering. It is worth pointing out though that these principles are not absolute. It isn’t simply a matter of a patient asking for euthanasia: all the statutory requirements have to be fulfilled.

B.2. The essential elements of the Euthanasia Act

a. Definition

The definition of euthanasia, as outlined in article 2 of the Act of 28 May 2002, is based on the Dutch Act and on the first opinion of the Advisory Committee[2]: euthanasia is the act by which a physician intentionally terminates the life of a patient, at the latter’s request, potentially expressed in a living will (art. 14).

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[1] The Act of 28 February 2014 extended the possibility to apply for euthanasia to minors.

[2] Opinion no. 1 of 12 May 1997 of the Belgian Advisory Committee on Bioethics concerning the advisability of a legal regulation on euthanasia (www.health.belgium.be/bioeth).

b. Essential conditions

Euthanasia must be performed by a physician: under no circumstances may he or she delegate that responsibility to someone else, e.g. a nurse.

The physician must make sure that the following three essential conditions have been fulfilled (art. 3):

1. The **request** must be voluntary, well-considered and repeated, and is not the result of any external pressure; the request must emanate from a legally competent patient;
2. The patient must invoke a situation of constant and unbearable physical or psychological **suffering** that cannot be alleviated.
3. The patient must find himself in a **medically hopeless situation** that is the consequence of a serious and incurable condition caused by accident or illness

It must be emphasised that there is a correlation between these three essential conditions, which we will discuss in greater detail under D.1.a.

c. Formal and procedural requirements

To ensure that the essential conditions of the Act are complied with, the legislator put a number of steps in place: written request, the attending physician's duty to inform, consultation of a second and sometimes third physician, additional conditions in cases where death is unlikely to occur in the near future, a meeting with the nursing team, possibly a meeting with close relatives, the obligation to record all the elements in the patient's medical file.

- The request must be made in writing and, if the patient is unable to write it himself, it must be written by a third party who has no material interest in the patient's death and in the presence of the physician.
- The physician to whom the request for euthanasia is addressed must have informed the patient about his/her health and life expectancy, the possible treatments and the possibility of palliative care beforehand. In other words, this obligation is about informing the patient about the availability of palliative care, not about compelling the patient to avail of palliative care. Furthermore, under the Patient Rights Act, the patient is free to refuse any and all care. That same Act also requires that the patient is provided with clear information, intelligible to the patient.
- The Euthanasia Act also stipulates that the physician in person must have several conversations with his/her patient to ascertain that the patient is determined to stick by his/her decision. Patients are in fact free to withdraw their request at any time. What's more, the request must be based on choice, one that is made after the patient has been provided with all the relevant information.

d. Role of the physicians consulted

The intervention of an independent physician, with a new perspective, has proven to be especially useful in situations where the attending physician may be too emotionally involved because he has been following up his patient for years, perhaps from long before he/she was diagnosed with the serious and incurable illness.

The physician consulted must be independent of the therapeutic relationship that developed between the patient and the physician who received the request for euthanasia and must have the relevant expertise to give an opinion on the illness in question.

Not only is he/she obliged to review the patient's medical record but he/she must also examine the patient, on the one hand, to verify the serious and incurable nature of the condition, and, on the other hand, to make sure that the patient is indeed experiencing constant, unbearable physical or psychological suffering that cannot be alleviated.

In the context of a euthanasia procedure in an adult or emancipated minor, these opinions are non-binding[3]. Although non-binding, opinions such as these constitute an important phase in the deliberations on the request for euthanasia. Once these opinions have been reviewed and given due consideration, it will be up to the physician and the patient to take a decision in accordance with the mandate they have been granted under the Euthanasia Act.

e. Death unlike to occur in the near future

The conditions governing situations where the physician does not expect the patient to die in the near future are more stringent. In cases like these, the intervention of a third physician, i.e. a second physician consulted, is required. By providing for this hypothesis, the legislator pursued two objectives: on the one hand, to avoid the trap of defining the concepts 'terminal stage' or 'terminally ill patient', and on the other hand, to allow more time and give more guarantees in cases where death is nothing more than a distant prospect.

- In cases where a patient is not expected to die in the near future, a period of no less than one month must be allowed between a patient's written request and the act of euthanasia.
- A third physician, a specialist in the disorder in question or a psychiatrist has to be consulted. His/her role will mainly consist in examining the voluntary nature of the request and establishing that there is no way that the patient's suffering can be alleviated.

The legislator did not compile a list of medical conditions that may qualify and did not define the psychological or physical nature of the suffering. So, in theory a psychiatric disorder can

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[3] The ruling of the Constitutional Court on the appeal against the extension of the Euthanasia Act to minors specifies that "where the paediatrician and child psychiatrist or psychologist consulted are of the opinion that the minor patient lacks the required the ability of discernment", the attending physician is not permitted to perform euthanasia on the patient in question, in other words, in this specific situation the opinion is binding.
(Ruling No 153/2015 of 29 October 2015 of the Constitutional Court on the appeal against the extension of the Euthanasia Act to minors: see paragraph B.24.8.2.)

come within the scope of the Act, provided that it is serious and incurable. In patients suffering from a psychiatric disorder, death is rarely imminent, except in a specific context (for instance if the patient is also suffering from cancer). It is for that reason that the, by law, always mandatory consultation of a second physician must be followed by a psychiatrist's opinion. The latter must review the medical file, examine the patient and ascertain that the constant and unbearable physical or psychological suffering cannot be alleviated and that the request was voluntary, well considered and repeated.

f. Federal Control and Evaluation Commission on Euthanasia (FCECE)

Within four working days of the euthanasia having been performed, the physician is obliged to submit a declaration to the Federal Control and Evaluation Commission on Euthanasia (FCECE) on how the Euthanasia Act was implemented. On the basis of the declarations submitted, the FCECE must examine whether the physicians acted in compliance with the statutory requirements and procedure.

On the basis of its examination of the euthanasia declaration, the Commission can reach one of the following conclusions:

1. The Commission decides that the declaration meets the statutory requirements in which case the anonymity of all parties concerned is preserved;
2. In the event of doubt, the Commission can suspend its decision: by simple majority, the FCECE may decide to revoke anonymity and ask the physician for further details before approving the declaration after all. The Commission has the authority to ask the attending physician for any element in the medical record file that relates to the euthanasia;
3. Where the Commission by a two-third majority decides that the conditions laid down in this Act have not been complied with, it will turn the file over to the public prosecutor of the place where the patient died.

In addition, as part of its evaluation remit, the FCECE produces a biennial report on the implementation of this Act for Parliament.

g. Freedom of conscience

The Act, which is based on respect for the autonomy and moral integrity (more specifically freedom of conscience) of a person who wishes euthanasia, accords the same respect for the autonomy and moral integrity of physicians or any other person who, in one way or another, may have to intervene in the euthanasia process.

Article 14 of the Act stipulates that no physician can be compelled to perform euthanasia and that no one is obliged to assist in euthanasia:

> *"Should the physician consulted refuse to perform euthanasia, he/she must inform, in a timely fashion, the patient or the potential persons of confidence while explaining*

> *his/her reasons. If the refusal is based on a medical reason, this is then entered into the patient's medical records.*
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> *The physician who refuses to proceed with a euthanasia request must communicate, when asked by the patient or the person of confidence, the patient's medical records to the physician designated by the patient or the person of confidence".*[4]

h. Euthanasia in minors

The Euthanasia Act was amended by the law of 28 February 2014 and now also allows (non-emancipated) minor patients to ask for euthanasia. However, euthanasia in minors is only permitted under the following conditions:

- Only if the minor patient has the ability of discernment[5] which must be confirmed by a child or youth psychiatrist or psychologist in writing; the (written) opinion of this psychiatrist/psychologist is binding on the attending physician[6];
- Death must be expected in the near future;
- Only in cases of physical suffering;
- With the consent of the parents (or legal representatives);
- Only the minor patient's actual request for euthanasia can be taken into consideration, to the exclusion of any prior living will.

The requests for an opinion discussed in this Opinion do not cover minor patients.

i. Concise comparison with the Dutch Act

Without going into detail, it seems useful to provide some information about the Dutch Act of 12 April 2001, entitled "Termination of Life on Request and Assisted Suicide Act" (WTL), given that this Act will be referred to in the remainder of this Opinion.[7] The Dutch legislator amended two articles in the Criminal Code that provide for termination of life on request and assisted suicide. To invoke these special absolving circumstances, the physician must act in compliance with the conditions of the Act (WTL). These entail that the physician (see art. 2, 1) must:

a. be satisfied that the patient's request was voluntary and well considered;
b. be satisfied that the patient's suffering is unbearable, with no prospect of improvement;

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[4] Unofficial translation of the Belgian Act on Euthanasia of 28 May 2002, see appendix III in "Euthanasia and Assisted Suicide: Lessons from Belgium", David A. Jones, Chris Gastmans, Calum Mac Kellar, Cambridge University Press, 2017.

[5] In paragraph B.3.1., p 28, of ruling no. 153/2015 of the Constitutional Court on the appeal against the extension of the Euthanasia Act to minors of 29 October 2015, this condition was clarified as follows (our translation): "…the minor patient who can be deemed capable of making a rational assessment of his/her interests, …" or "To make a valid request, one must be able to rationally assess one's interests".

[6] Ruling No 153/2015 of the Constitutional Court on the appeal against the extension of the Euthanasia Act to minors of 29 October 2015, more specifically paragraph B.24.8.2.

[7] There are a number of important differences between the Belgian and the Dutch Acts which we won't delve into any further here.

c. have informed the patient about his/her situation and prognosis;
d. have come to the conclusion, together with the patient, that there is no other reasonable alternative in the patient's situation;
e. have consulted at least one other independent physician who must see the patient and give a written opinion on whether the due care criteria set out in (a) to (d) have been fulfilled;
f. have exercised due medical care and attention in terminating the patient's life or assisting in his/her suicide.

The Dutch Act does not stipulate that the physician consulted must be a psychiatrist. The *Code of Practice* of the Regional Euthanasia Review Committees (*Regionale Toetsingscommissies Euthanasie*) does make a recommendation to that effect however.[8]

The Act talks about suffering and not about a medical condition, but legal doctrine and case law, and more specifically the doctrine developed by the five Regional Review Committees, stipulates that a patient's suffering must have a medical dimension, irrespective of whether it is somatic or psychiatric in nature.[9] The Dutch Act does not differentiate between patients who are expected to die in the near future or those who are not: at least one physician consulted is required, regardless of whether the patient is in the terminal stage or not. There is no statutory waiting period between the request for euthanasia and its execution. The Dutch physicians did not ask for anonymity when reporting euthanasia cases. Each reported euthanasia case gives rise to a substantiated opinion from the competent Regional Review Committee.

B.3. State of the art in the current debate

The Euthanasia Act has been widely welcomed by the Belgian public, the medical world and the political world alike[10]. The Flemish Palliative Care Federation has stated that euthanasia

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[8] Code of Practice, *Regionale Toetsingscommissies Euthanasie*, The Hague, 2015, p 26, § 4.3. Patients suffering from a psychiatric disorder: "Besides consulting a regular independent physician who assesses whether all the due care criteria mentioned in sections 3.2 to 3.5 have been met, the physician must also consult an independent psychiatrist, to assess the patient's decisional competence regarding the request, and whether he is suffering with no prospect of improvement. In order to avoid placing an unnecessary burden on the patient, it might be preferable to consult an independent physician (or SCEN physician) who is a qualified psychiatrist."

[9] Meanwhile the Dutch Minister for Health, Welfare and Sport and the Minister for Security and Justice wrote to the Lower House of the Dutch Parliament on 12 October 2016 announcing that the government, in consultation with various parties, wanted to develop "a new legal framework" that would facilitate assisted suicide (including euthanasia) for people who consider their "life completed", even if there is no question of a medical condition ("no question of a medical basis for the hopeless and unbearable suffering"). This matter is still very much being debated. We will revert to it in the course of our ethical debate. See https://rijksoverheid.nl/actueel/nieuws/2016/10/12/kabinet-ruimte-voor-hulp-bij-zelfdoding-bij-voltooid-leven.

[10] Cohen, J.; Van Landeghem, P.; Carpentier, N.; Deliens, L. (2014), "Public acceptance of euthanasia in Europe: a survey study in 47 countries", *International Journal of Public Health*, (2014)59, pp. 143-156: *"Relatively high acceptance was found in a small cluster of Western European countries, including the three countries that have legalized euthanasia and Denmark, France, Sweden and Spain. In a large part of Europe public acceptance was relatively low to moderate. Comparison with the results of previous EVS wave (1999) suggests a tendency towards*

could be accepted in the context of palliative care[11]. On 22 March 2003, the Order of Physicians issued its "Opinion on palliative care, euthanasia and other medical end-of-life-related decisions"[12].

However, the questions that are cropping in the current political and societal debate in Belgium go beyond the issue presented to the Committee. It concerns the following, non-exhaustive list of questions:

On the one hand:

- Abolition of the limited validity of a prior living will regarding euthanasia, a simplification of how the living will must be drawn up and a broadening of the scope to also include people suffering from severe brain injury (more specifically people suffering from dementia) [13];
- Conscientious objection clause and its limitations with the result that euthanasia can be refused in certain care institutions;[14]
- Introduction of a legally (i.e. not 'for ethical reasons') referral by the attending physician to a colleague physician if the attending physician refuses to comply with a request for euthanasia filed in accordance with the law.[15]

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a polarization in Europe, with most of Western Europe becoming more permissive and most of Eastern Europe becoming less permissive." (p 143)

[11] Flemish Palliative Care Federation (2003). Dealing with euthanasia and other forms of medically-assisted dying [in Dutch]:
www.palliatief.be/accounts/143/attachments/Publicaties/euthanasie_-_standpunt_federatie.doc.
[for the translation into English, see http://www.consciencelaws.org/background/procedures/assist008-007.aspx].
See also Assisted dying – the current situation in Flanders: euthanasia embedded in palliative care, 2013:
http://www.palliatief.be/accounts/143/attachments/Publicaties/ejpc_20_6_vdb_am_md_gh.pdf
See also the vision statement 'On Palliative Care and Euthanasia', 2013:
http://www.palliatief.be/accounts/143/attachments/Publicaties/visietekst_onpalliativecare_and_euthanasia_27_05_2013_def.pdf.

See also Jan L. Bernheim, Wim Distelmans, Arsène Mullie, Johan Bilsen, Luc Deliens. Development of Palliative Care and Legalisation of Euthanasia: Antagonism or Synergy? *British Medical Journal* Vol. 336, No. 7649 (Apr. 19, 2008), pp. 864-867.

[12] https://ordomedic.be/nl/adviezen/advies/advies-betreffende-palliatieve-zorg-euthanasie-en-andere-medische-beslissingen-omtrent-het-levenseinde

[13] See the legislative proposals of 10 April 2015 to amend the Euthanasia Act of 28 May 2002:

- persons affected by cerebral disorders who have become unable to express their will: http://www.dekamer.be/FLWB/PDF/54/1013/54K1013001.pdf
- the duration of the living will: http://www.dekamer.be/FLWB/PDF/54/1014/54K1014001.pdf

See the legislative proposal of 23 February 2016 to amend the Euthanasia Act of 28 May 2002 with a view to cancelling the living will's maximum validity period of 5 years and to allow the patient to decide on its validity: http://www.dekamer.be/FLWB/PDF/54/1675/54K1675001.pdf

See the legislative proposal of 13 May 2016 to amend the Euthanasia Act of 28 May 2002 to cancel the validity period of the living will:
http://www.dekamer.be/FLWB/PDF/54/1830/54K1830001.pdf

[14] The first two questions were presented to the Senate in the form of proposals during the 2010-2014 government term. The Joint Committees Justice and Social Affairs conducted hearings on all the questions from 28 February until 12 May 2013. In the end, only the issue of minors was retained for legislation purposes.

See the legislative proposal of 23 February 2016 to amend the Euthanasia Act of 28 May 2002 and the Coordinated Act of 10 July 2008 on hospitals and other care institutions with a view to safeguarding the conscientious objection clause: http://www.dekamer.be/FLWB/PDF/54/1676/54K1676001.pdf.

On this point, see also the Advisory Committee's Opinion no. 59 of 27 January 2014 on ethical aspects of the application of the Law of 28 May 2002 on euthanasia (www.health.belgium.be/bioeth).

[15] See the legislative proposal of 10 April 2015 to amend the Euthanasia with regard to the referral obligation: http://www.dekamer.be/FLWB/PDF/54/1015/54K1015001.pdf

- Monitoring the practice of continuous sedation;[16]

On the other hand:

- The question to remove the possibility of euthanasia for psychiatric patients;[17]
- Criticism of the Federal Control and Evaluation Commission on Euthanasia [FCECE] set up in application of the Euthanasia Act and to ensure the monitoring provided for under this Act[18].

Hasty conclusions have to be avoided though. These could be provoked by the mediatisation of certain cases, which are rarely exhaustively documented, in part because the professional care providers who are au fait with the entire file are not allowed to comment because they are bound by professional secrecy.

See the legislative proposal of 23 February 2016 to amend the Euthanasia Act setting a period of time within which the physician is obliged to respond to a patient's request for euthanasia and refer the medical file to a colleague if he/she refuses to comply with the request: http://www.dekamer.be/FLWB/PDF/54/1677/54K1677001.pdf

See the legislative proposal of 13 May 2016 to amend the Euthanasia Act of 28 May 2002 to compel a physician, who invokes the conscientious objection clause, to refer the patient to another physician: http://www.dekamer.be/FLWB/PDF/54/1832/54K1832001.pdf

[16] Scientific studies have shown that continuous sedation gives rise to various problems. See for instance: Raus, Kasper; Sterckx, Sigrid & Mortier, Freddy (2011), "Continuous deep sedation at the end of life and the natural death hypothesis", *Bioethics*, vol. 26, 6), pp. 329-336. See also Anquinet, L.; Raus, K.; Sterckx, S.; Deliens, L. & Rietjens, J.A. (2012), "Similarities and differences between continuous sedation until death and euthanasia: professional caregivers' attitudes and experiences. A focus group study in Flanders, Belgium", *Palliative Medicine*, vol. 27(6), pp. 553 - 561.

[17] Bazan, Ariane; Van de Vijver, Gertrudis; Lemmens, Willem; Rénuart, Noémie; initatiors, several signatories, (2015), "Euthanasie bij psychisch lijden: een wankel wettelijk kader en maatschappelijke ondermijnende gevolgen [Euthanasia for mental suffering, a shaky legal framework and detrimental social consequences]", *Artsenkrant*, 25 September 2015, no. 2420: p 42

See also Bazan, Ariane; Van de Vijver, Gertrudis; Lemmens, Willem; 65 signatories (2015), "De dood als therapie [Death as therapy]?"; *De Morgen,* 8 December 2015, p 32.

Vandenberghe, Joris (2015), "Waarom ik 'stop euthanasia bij psychisch lijden' niet onderteken [Why I shan't sign 'stop euthanasia for psychological suffering']", *De Morgen*, 9 December 2015, p 2.

See also Braeckman, Johan; Ravelingien, An; Boudry, Maarten and more than 250 signatories (2015). "Banaliseer psychisch lijden niet [Do not trivialise psychological suffering]", De Morgen, 11 December 2015.

[18] Raus, Kasper; Sterckx, Sigrid; Desmet, Marc; Devisch, Ignaas; Focquaert, Farah; Haekens, An; Huysmans, Gert; Lisaerde, Jo; Mullie, Senne; Nys, Herman; Pennings, Guido; Provoost, Veerle; Ravelingien, An; Schotsmans, Paul; Vandenberghe, Joris; Vanden Berghe, Paul; Van Den Noortgate, Nele; Vanderhaegen, Bert, "Mogen we nog vragen stellen [Are we even allowed to ask questions]?", *De Standaard*, 15 November 2016, p 37.

Raus, Kasper; Sterckx, Sigrid; Beyen, Anne; De Lepeleire, Jan; Desmet, Marc; Devisch, Ignaas; Focquaert, Farah; Ghijsebrechts, Gert; Haekens, An; Huysmans, Gert; Lisaerde, Jo; Mullie, Senne; Provoost, Veerle; Ravelingien, An; Schotsmans, Paul; Vandenberghe, Joris; Van Den Noortgate, Nele; Vanden Berghe, Paul, Vanderhaegen, Bert, "Komt nagenoeg iedereen van boven de 70 jaar nu in aanmerking voor euthanasie [Does just about everyone over the age of 70 qualify for euthanasia now?]?", *Knack*, 15 November 2016.

Distelmans, Wim, "Zindelijke vragen graag [Clear questions please]", *De Standaard*, 18 November 2017.

C. Answer to the first two questions

This Opinion does not look into the topic of assisted suicide: physician-assisted suicide has not been regulated by law yet. However, both the Order of Physicians and the Federal Control and Evaluation Commission on Euthanasia (FCECE) equate it to euthanasia, provided the relevant conditions are fulfilled. They believe that physicians should assist patients if they wish to take the lethal product and must remain by the patient's side until death has been confirmed. Prescribing medication - barbiturates syrup - without the physician being present when it is taken remains a decisively illegal practice according to the Order of Physicians and the FCECE.

It was decided within the Committee not to discuss the issue of persons who are not within the terms of the Euthanasia Act, but still request assisted suicide because they either find their lives completed or mention tiredness of life as sole motive. While that debate has been raging in Dutch society for twenty years now[19], it has only begun to raise its head in Belgium.

a. Question 1: Does the legal basis to obtain euthanasia vary in cases where also the partner's request for euthanasia can be granted?

In her oral question to the minister, Senator Elke Sleurs referred to a mediatised euthanasia case where a couple asked for euthanasia. The Committee points out that whether it concerns a couple, married or not, is irrelevant here. Each request is unique, must be examined on its own merit and must meet the legal requirements, like any other request for euthanasia. The fact that it concerned a couple, married or not, is irrelevant to the examination of the conditions the legislator laid down. If the partner's personal situation does not meet the statutory requirements for euthanasia, then there is no legal basis to grant the euthanasia request.

The Committee understands the anxiety of the surviving partner to live on alone and the resulting psychological suffering, but these are, however, in themselves insufficient to justify euthanasia.

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[19] See eg.the debate in the Dutch newsprogram *Nieuwsuur*: http://nos.nl/uitzending/15529-nieuwsuur.html.
See also the letter from the Dutch Minister for Health, Welfare and Sport and the Minister for Security and Justice of 12 October 2016 to the Lower House of the Dutch Parliament concerning the development of a new legal framework for assisted suicide (including euthanasia) for people who consider their life completed. See https://rijksoverheid.nl/actueel/nieuws/2016/10/12/kabinet-ruimte-voor-hulp-bij-zelfdoding-bij-voltooid-leven.

b. Question 2: What is the legal basis to obtain euthanasia if the applicant is not terminally ill?

It is worth remembering that the legislator never intended to include the concept ‘terminal stage’ in the Euthanasia Act. Admittedly, the Act does lay down additional conditions if the physician is of the opinion that death is unlikely to occur in the near future. In that case, he/she is not only obliged to consult a second physician, who, on the one hand, must examine the serious and incurable nature of the medical condition, and, on the other hand, establish that the physical or psychological suffering cannot be alleviated, but also obliged to call in a third physician to review the medical file, examine the patient and give his/her opinion on the constant, unbearable and unalleviable nature of the suffering, and on the quality of the request, i.e. whether it was voluntary, well-considered and repeated. This third physician must either be a psychiatrist or a consultant specialised in the pathology in question and must be independent of the patient, the attending physician and the second physician. Furthermore, a period of one month must lapse between the written request for euthanasia and the act itself. In other words, the Act does not stipulate that the patient must be in a terminal stage.

D. Question 3: Is there a societal need to clarify the concept of constant and unbearable psychological suffering, resulting from a serious and incurable disorder caused by accident or illness, that cannot be alleviated?

The Committee discussed the opportunity of an opinion on the basis of the question posed by Senator Elke Sleurs. **Some members** were of the opinion that the issue can be put to bed on the basis of the Euthanasia Act of 28 May 2002, without necessarily starting a debate which they believe would trend toward the categorisation or medicalisation of the various types of suffering.

Other members believed that it would be useful to start by clarifying the concepts that feature in the Euthanasia Act of 28 May 2002 on the basis of scientific literature. These members were of the opinion that it was important to include the findings of empirical studies on the concept of suffering in the context of euthanasia, the evolution of the frequency of euthanasia in Flanders and on tiredness of life. The members in question are of the opinion that these clarifications will provide an excellent framework for the subsequent ethical debate under D.6.

D.1. Clarification of the concepts suffering, capacity, diagnosability and incurability, tiredness of life and completed life

a. Suffering

a.1. <u>Preliminary comment: psychological suffering versus psychiatric disorder</u>

Before looking into the usefulness of clarifying the concept psychological suffering it must be pointed out that psychological suffering is often confused with a psychiatric illness or disorder. Psychological suffering can just as easily be caused by a somatic pathology as by a psychiatric disorder, just like psychiatric disorders can give rise to physical suffering. Anorexia nervosa would be a prime example of that. In other words, a clear distinction must be made between a medical condition and suffering.

a.2. Point of view of the members who do not see the need to clarify the concept ‘psychological suffering’

Without dismissing the debate, **some members** fear that attempts to define and categorise psychological suffering would only muddy the waters and may ultimately lead to patients suffering from a psychiatric disorder being denied euthanasia.

They point out that physical or psychological suffering is highly subjective: in principle it is the patient who is best placed to assess the unbearable nature of his/her suffering. However, this subjective nature goes hand in hand with an assessment, based on knowledge and experience, by professional care providers, the attending physician and the physician consulted who are inevitably faced with the following question: would it not be possible to alleviate the suffering, to propose a therapy that will ease the physical suffering or relieve the pain or will alleviate the psychological suffering?

The euthanasia declarations the Federal Control and Evaluation Commission on Euthanasia (FCECE) receives often mention both physical and psychological suffering, with a preponderance of psychological suffering: while medicine can ease physical pain in many cases, it is often powerless when it comes to psychological suffering, such as despair, dependence, loss of dignity. The precondition for this physical or psychological requirement under the Euthanasia Act of 28 May 2002 is that there must be a **causal link** between the (serious and incurable) medical condition and the suffering.[20]

They emphasise that the three essential conditions (i.e. a well-considered request, a serious and incurable medical condition, and constant and unbearable suffering) are intrinsically linked, with the result that, in respect of each euthanasia request, the connection between those three essential conditions must be examined.

a.3. Point of view of the members who do believe it is necessary to clarify the concept ‘psychological suffering’

Other members believe that there are various reasons why there is a pressing societal need to clarify this concept. After all, both ‘psychological suffering’ and ‘unbearable suffering’ can take different forms.

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[20] In a certain internee’s situation - a case that received extensive media coverage - the legal requirements to qualify for euthanasia did not seem to be fulfilled because the patient’s suffering was the result of his incarceration and the fact that he was denied proper treatment. See: La prison face à la demande d'euthanasie [Prisons and requests for euthanasia], Jacqueline Herremans, Justice en ligne, http://www.justice-en-ligne.be/article761.html.

These members are aware that, as soon as one embarks on an analysis of concepts like 'suffering', 'psychological suffering', and 'mental suffering' it doesn't take long to end up in a conceptual maze. Literature contains a wide range of terms and concepts relating to psychological suffering, without there being any consensus on how to best define or use these concepts. Examples are 'psychological pain' (Mee et al. 2006), 'psychogenic pain' (Joffe & Sandler 1967), 'existential suffering' (Kissane 2012), 'psycho-existential suffering' (Murata & Morita 2006) and 'social suffering' (Bourdieu 1999).

The conceptual line between suffering and pain is often extremely fine since both terms have overlapping and similar meanings. There is a tendency to associate *pain* with a *physical* experience, and to regard pain as synonymous with an unpleasant physical experience. *Suffering*, on the other hand, is often considered to be a broader and more compound phenomenon which, inter alia, has physical, moral and emotional dimensions. Dees and colleagues (2009) conducted a *review* of the most important literature on 'unbearable suffering' (an extremely important concept in the context of the Euthanasia Act) and produced a summary of the various ways the concept 'suffering' was used or defined. Their classification clearly shows that there are many different definitions of the concept which all have one thing in common: i.e. that they describe suffering as a broad phenomenon, which can also include physical pain. People who are in pain can also suffer, while people who suffer can also experience pain, but, in either case, *not necessarily* the two will apply.

This brings us back to the specific question of what the concept 'psychological suffering' actually means. The legislator did not define it but merely contrasted it with physical suffering. Thus, psychological suffering is *non-physical suffering*, but that still leaves us with an extremely broad domain. After all, **psychological suffering can be the result of a medically diagnosable somatic condition or a medically diagnosable psychiatric disorder (e.g. clinical depression), but it can also entail suffering that is not caused by a demonstrable or diagnosable (physical or psychiatric) condition or illness.** For conceptual clarity and demarcation purposes, the latter forms of suffering could be qualified as 'mental' suffering, which in turn comprises various types of suffering, among which emotional, existential and spiritual suffering. It must be stated that the differences between the aforementioned types of suffering are partially artificial since suffering is rarely *purely* physical or *purely* psychological or *purely* mental. Nonetheless, it could prove useful to reflect on these differences if we want to give an unambiguous explanation of what the concept 'physical suffering' could mean and actually does mean in the context of the Euthanasia Act. The million dollar question is whether there are forms of psychological suffering that are not a justified indication for euthanasia.

The official Dutch medical association (*Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst* or KNMG), which fulfils a number of functions the Order of

Physicians ensures in our country, makes the following relevant comment about requests for euthanasia from people experiencing non-physical suffering (our translation):

> *"Assessing whether the request was well-considered and whether the suffering these categories of patient[s] endure is indeed hopeless and unbearable tends to be far more complex than in patients whose suffering is caused by somatic issues and complaints."* (KNMG 2011, p 7)

b. Ability of discernment

To ascertain whether the request was well considered one must also be able to assess whether the person concerned has the relevant ability of discernment. In this respect it must be pointed out that, in some cases, psychological suffering (e.g. as a result of a psychiatric disorder) can reduce or impair a person's ability of discernment. What is its relevance in the context of the application of the Euthanasia Act?

Based on the well-known *Diagnostic and Statistical Manual of Mental Disorders* (DSM 5) (American Psychiatric Association 2013), the wish to die is one of the indications for a diagnosis of depression. When someone is suffering from depression, the wish to die, and the ensuing request for euthanasia, can be a symptom of the condition rather than a well-considered expression of will in other words. In cases like these, patients can hardly be deemed to have the capacity to decide on their own death.

Admittedly, depression does not necessarily mean that the patient lacks the required ability of discernment but, in cases where a person's ability of discernment is questionable, there is a clear reason to deny euthanasia since the Belgian Euthanasia Act requires a voluntary, well-considered and repeated request from a legally competent patient. It goes without saying that these comments apply to all patients who formulate a request for euthanasia, whether they are suffering from a psychiatric disorder or not.

Even though suicidal tendencies and the wish to die can be associated with depression, they, in essence, do not constitute proof that the person lacks ability of discernment. This, for one, has been recognised by the Netherlands Psychiatric Association (*Nederlandse Vereniging voor Psychiatrie*) in a guideline on how to deal with requests for assisted suicide from patients suffering from a psychiatric illness (our translation):

> *"Suicidality is not by definition a psychopathological phenomenon. According to the commission it is possible that, in exceptional cases, a request for assisted suicide, expressed by a psychiatric patient, may be the result of a careful deliberation. Even though many death wishes expressed by psychiatric patients are temporary and, hence, transient, in nature, the commission takes the view that, in some cases, a*

> *death wish can be sustained and, ultimately, does not go away."* (Nederlandse Vereniging voor Psychiatrie 2009, p 28)

It is an accepted legal and ethical principle that a person is competent until proven otherwise. This principle also constitutes the basis for the reform of the protection status of people who have been declared legally incompetent, as introduced by the Act of 17 March 2013. This Act aims to tailor the protective measures to the competence[21] of the people concerned to ensure that they, insofar as possible, do get a say in the decision-making process or the decisions. Studies on patients suffering from psychiatric disorders show that they are able to form a reliable opinion about their own quality of life (Baumstarck et al. 2013) and also that, in spite of the fact that the ability of discernment of the people concerned may be compromised at times, this is not necessarily *always* the case either (Grisso & Appelbaum 1995). What's more, ability of discernment is a task-specific matter. Whether a person has the relevant ability of discernment or not must be examined on a case-by-case basis. A person may be capable of taking certain decisions yet unable to make others. In other words, there is no valid reason to assume that people with a psychiatric disorder are necessarily incapable or less capable of taking decisions.[22]

c. Diagnosing a serious and incurable medical condition

Even though the term does not feature in art. 3(1) of the Euthanasia Act as such, diagnosability is an important criterion since requests for euthanasia are valid only if the suffering is the consequence of an illness (or accident), but not if the suffering is not caused by illness (or accident). In this context, the question could arise what the (in the context of the Euthanasia Act) relevant differences between suffering *caused by a diagnosable illness* and suffering *without a diagnosable illness* are. This question automatically brings us to the issue where the field of medicine and medical expertise ends, and, hence, to the issue where the physician's role ends or should end.

It could be said that medicine deals with illnesses and medical conditions, with the result that *suffering in absence of a diagnosable (physical or psychiatric) illness or condition is beyond the scope of medicine*. According to this argument, patients who experience psychological suffering *without* a diagnosable illness or whose suffering is not *caused* by illness and who ask for euthanasia therefore have nothing to gain from a *medical* solution to their problem, but need to be helped by *people other than physicians* (e.g. a social worker, a psychologist, a chaplain, a moral counsellor or others) if their suffering is to be alleviated. Some believe that

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[21] Act of 17 March 2013 reforming the provisions regarding incompetence and introducing a new protection status in line with human dignity, art. 39, e) (our translation): "competence: the authority to exercise one's rights and obligations in person and independently."

[22] See also the arguments by Schuklenk and van de Vathorst in this respect (2015).

extending the medical field to suffering that is not (or not mainly) caused by illness, will result in excessive and undesirable medicalisation (Szasz 2007). We will come back to this issue in our ethical debate.

It must also be noted that medical conditions can often be diagnosed *objectively* by means of, inter alia, clinical observation, medical imaging, blood tests, etc., while the assessment of suffering in the absence of an illness or condition will always be *subjective*.[23] It is important to bear in mind that it is *the illness and not the suffering that is diagnosed*. *Suffering* (whether physical or psychological in nature) *cannot* be identified or measured *objectively*; a diagnosis is nothing other than the *identification of an illness or a condition***.**

Only suffering that (inter alia) meets the requirement "***resulting from** a serious and incurable disorder caused by accident or illness*" (art. 3(1)) can qualify as legal grounds for euthanasia. The assessment of the significance of the link between a diagnosable illness and the unbearable suffering therefore continues to constitute the basis on which a physician shall consider a request for euthanasia in a favourable light.

Some experts deem that there is an important and even fundamental difference between diagnosable *somatic* illnesses and various *psychiatric* disorders that may indeed have been objectively diagnosed but where the specific nature of the therapeutic relationship between physician and patient calls for particular care on the part of the physician before a request for euthanasia can be met with a favourable response. In our country, not only certain psychiatrists, but also some physicians specialised in other fields and ethicists are wondering whether the current legislation contains enough safeguards to prevent that a request for euthanasia for reasons of unbearable suffering caused by a psychiatric disorder is granted too quickly.[24]

Art. 3(1) of the Euthanasia Act stipulates that the condition the patient is suffering from must be *serious and incurable*. Some commentators dismiss euthanasia for non-physical suffering without a diagnosable condition on the grounds that, in this type of suffering, it is impossible to conclusively state that it is beyond cure. Kelly & McLoughlin (2002) argue that, even in cases where a patient's suffering is *caused by* a diagnosable psychiatric disorder, this can be an extremely tricky matter:

> *"In the case of an individual patient, it remains extremely difficult to predict whether therapy will produce an early response, a delayed response or no response [...]. It is*

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[23] The most commonly used tool to diagnose mental disorders is the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association 2013). This book has been the subject of widespread criticism because, in spite of its apparent objectivity, it leaves plenty of room for subjectivity and interpretation (Greenberg 2013), a.o. because the diagnostic criteria for certain conditions are extremely vague.

[24] See e.g. Claes et al. 2015, a letter to the editor in chief of the magazine *BMJ Open*, which published a study of 100 euthanasia requests from psychiatric patients in Belgium (Thienpont et al. 2015).

> *impossible to predict which patients will undergo spontaneous remission and when this will happen. These uncertainties are far more pronounced in psychiatric practice than in medical practice, to the extent that it is essentially impossible to describe any psychiatric illness as incurable."* (Kelly and McLoughlin 2002, p 279)

The same could possibly be said for psychological suffering without a diagnosable condition, and, hence, could be a valid argument against euthanasia for this type of suffering. In *physical* conditions it will often be easier to establish when they are incurable, either because all therapeutic options have been exhausted or because the patient's prognosis is so poor that the new therapy wouldn't take effect in time. In the case of *psychological suffering* there tends to be a wider range of therapies that can be resorted to and, as Kelly & McLoughlin noted, it can never be conclusively excluded that the patient's suffering might alleviate spontaneously. This is all the more the case because the majority of psychiatric patients are not terminally ill and the long-term evolution of their condition is often difficult to predict.

The Netherlands Psychiatric Association (Nederlandse Vereniging voor Psychiatrie - NVvP) produced a guideline[25] on how to deal with assisted-suicide requests from psychiatric patients. One of the crucial questions is at what moment in time will a psychiatrist be able to state that all treatment options have been exhausted and that the condition is beyond cure. On that issue, the **Assisted Suicide Committee of the Netherlands Psychiatric Association** states as follows (our translation):

> *"Keynote is that, according to medical and scientific understanding, the patient has received all the appropriate treatment options and that these have proven to be ineffective. [...] [Hereafter] a number of general guidelines the psychiatrist can refer to during his assessment.* ***According to the Committee, a patient can only be deemed untreatable if the following interventions have been tried:***
>
> - ***all indicated regular biological therapies;***
> - ***all indicated psychotherapeutic therapies;***
> - ***social interventions that can make the suffering more bearable.***
>
> *The practitioner shall in any case base himself on the guidelines and consensus documents the professional association issued. The therapies must qualify as state of the art. In a patient suffering from a depressive disorder for instance, biological therapy shall in any event have included: a modern antidepressant, a tricyclic antidepressant with blood level checks, an augmentation strategy with lithium for instance, a monoamine oxidase inhibitor and electroconvulsive therapy. [...] Furthermore, in the case of a patient suffering from depression, he must check whether the regular forms of psychotherapy, such as interpersonal therapy, cognitive*

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[25] The NVvP drew up this guideline on the basis of existing therapy-related practices and scientific literature and in function of the relevant Dutch legislation.

> *(behavioural) therapy or, where indicated, other forms of therapy have been provided by a qualified therapist."*[26] (emphasis added)

The question is what conclusions a physician can either or not draw with regard to the incurable nature of a disorder in cases where a patient refuses treatment. This question will be exhaustively dealt with in the ethical debate.

d. Tiredness of life and completed life

Some use the terms 'tiredness of life' and 'completed life' as synonyms. The question is: is there a difference between the two? People can be weary of life whether they are ill or not. Likewise, people can feel that they have lived their life whether they are sick or not. So what is the difference between tiredness of life and completed life? 'Completed life' is a term that is often used in the Netherlands because that was also what the advisory committee chaired by Prof. Schnabel was called. But what is the difference between the two?

In Belgium

In an article that was published in the *Tijdschrift voor Geneeskunde* [Medical Journal] in 2016, a number of Flemish experts from the 'Palliative care and Geriatrics' Working Party, set up by the Federation Palliative Care Flanders, use the unambiguous definition of tiredness of life suggested by Evelien Delbeke (Van Den Noortgate et al. 2016). She describes tiredness of life as (our translation) "psychological suffering by a person who, as a result of (a combination of) medical and/or non-medical factors, no longer experiences quality of life or whose quality of life has deteriorated to such an extent that they prefer death to life"[27]. According to this definition, the presence of suffering is an essential characteristic of tiredness of life (Van Den Noortgate et al. 2016, p 146). This definition also tells us that tiredness of life can even present itself in people who do not have any medical issues.

In the Netherlands

In their *Code of Practice* (April 2015), the Dutch Regional Euthanasia Review Committees states:

> "As the legislative history of the Act makes clear, the expression 'finished with life' refers to the situation of people who, often at an advanced age and without the

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[26] Netherlands Psychiatric Association, Assisted Suicide Committee (2009), Directive "Dealing with requests for assisted suicide from patients with a psychiatric disorder", pp. 37-38.

[27] Delbeke, E. "Hulp bij zelfdoding en levensmoeheid [Assisted Suicide and Tiredness of life]" in: "Juridische aspecten van zorgverlening aan het levenseinde [Legal aspects of care at the end of life]". Mortsel: Published by Intersentia, 2012: 395-411.

> medical profession having established that they have a disease or disorder that is accompanied by great suffering, have come to the conclusion that the value of their lives to them has decreased to the point where they would rather die than carry on living."[28]

The Dutch Advisory Committee "Completed Life" (Schnabel) refers to the description given by the Dutch Voluntary Euthanasia Society (*Nederlandse Vereniging voor een Vrijwillig Levenseinde* - NVVE) (our translation):

> "*In a report produced for the advisory committee, the NVVE stresses that the term 'completed life' is impossible to define*".[29]
>
> *"It is an existential suffering, which does not necessarily have a medical cause, where the person perceives his situation as hopeless and where all appropriate alternative treatment options have been exhausted. People who feel that their life has been completed are usually no longer able to group, organise themselves or to stand up for themselves. The people in question tend to be at an advanced age, unattached, isolated, housebound, visually and aurally impaired and are simply awaiting death."*[30]

However, other stakeholders and experts use different definitions and concepts. For that reason, the Dutch Advisory Committee "Completed Life" concludes that (our translation)

> *"The concept 'completed life' is an umbrella concept that is used to cover situations where everything has happened and has been done and where life can be concluded in satisfaction (not necessarily by means of suicide or assisted suicide) and situations where life has been so fraught with problems that one has become adverse to life and is done with it."*[31]
>
> *"We are talking about people who tend to be at an advanced age and who feel that they no longer have any perspective on life and, as a result, have developed a persistent, active wish to die".*[32]

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[28] Regional Euthanasia Review Committees, "Code of Practice", The Hague, April 2015 https://www.euthanasiecommissie.nl/de-toetsingscommissies/uitspraken/brochures/brochures/code-of-practice/1/code-of-practice, p 32.

[29] Adviescommissie voltooid leven [Advisory Committee Completed Life]. "Voltooid leven. Over hulp bij zelfdoding aan mensen die hun leven voltooid achten [Completed life. On assisted suicide for people who consider their life completed]", The Hague, January 2016, https://www.rijksoverheid.nl/onderwerpen/levenseinde-en-euthanasie/documenten/rapporten/2016/02/04/rapport-adviescommissie-voltooid-leven, p 30.

[30] Quote from the "Rapport - Voltooid leven, de ervaring. Een analyse van de rapportages van het NVVE adviescentrum [Report - Completed life, the experience. An analysis of the reports of the NVVE Advice centre]", NVVE ,17 July 2015 (p 4) referred to in the report of the 'Adviescommissie voltooid leven' [Advisory Committee Completed Life]: "Voltooid leven. Over hulp bij zelfdoding aan mensen die hun leven voltooid achten [Completed life. On assisted suicide for people who consider their life completed]", The Hague, January 2016, p 30.

[31] Adviescommissie voltooid leven [Advisory Committee Completed Life]. "Voltooid leven. Over hulp bij zelfdoding aan mensen die hun leven voltooid achten [Completed life. On assisted suicide for people who consider their life completed]", The Hague, January 2016, https://www.rijksoverheid.nl/onderwerpen/levenseinde-en-euthanasie/documenten/rapporten/2016/02/04/rapport-adviescommissie-voltooid-leven, p 33.

[32] Ibidem, p 34.

On behalf of the government, the Minister for Health, Welfare and Sport, Mrs Schippers, and the Minister for Security and Justice, Mr Van der Steur, responded to the conclusion of the advisory committee[33] in October 2016. In their letter, they discuss the idea of developing a separate framework for assisted suicide *"for the group of people who consider their life completed, but are not suffering from a series of age-related complaints, or whose suffering is not caused by a medical condition, but by a hopeless and unbearable suffering from life and, hence, have developed an active wish to die"* (letter from the Cabinet p 4, our translation). It concerns people who *"consider their life completed because they are for instance suffering as a result of having lost their partner and loved ones, their meaningful contacts, because of tiredness and apathy that cannot be attributed to a medical condition"* (letter from the Cabinet p 5, our translation). "*This group also includes people who have had enough and for whom each day is a day they are simply waiting for death to arrive"* (letter from the Cabinet p 5, our translation).

In her doctoral thesis entitled 'Ready to give up on life: a study into the lived experience of older people who consider their lives to be completed and no longer worth living' at the University of Humanistic Studies in Utrecht (van Wijngaarden 2016b), Els van Wijngaarden inter alia concludes that the three terms[34] completed life, tiredness of life and suffering from life all have their limitations. In the English summary of her thesis she concludes as follows:

> *"We conclude by evaluating the terms 'completed life', 'tiredness of life' and 'suffering from life'. All these terms fall short in describing the phenomenon at stake. Most importantly, our study has shown that a so-called completed life is not at all about 'fulfilment' or 'completeness'; instead it is about existential suffering. Besides, the term completed life suggests a firm and well-established decision – clearly marked in time – that life is 'over', as if one has decided that 'it is done'. However, in real life all kinds of ambiguities and ambivalences appeared to be present. The decision-making process is better characterized as a constant dilemma.*
> *Finally, the term simply ignores the fact that someone is still living on. At least at a biological level, life is not completed yet. But also on the biographical level, life has not stopped yet. Actually, the older people 'work on' their own biography very consciously: for example, by active engagement in the political debate on completed life in old age; by joining our research project; and by organizing their death and their funeral in a way they personally prefer. The self-directed death seems not only a way to regain control, but also a way to 'work on' a coherent end*

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[33] See https://rijksoverheid.nl/actueel/nieuws/2016/10/12/kabinet-ruimte-voor-hulp-bij-zelfdoding-bij-voltooid-leven.

[34] In the general introduction to her thesis, she defines 19 terms such as 'tiredness of life', 'suffering from life', 'completed life' (see *1.4. Defining the terms*).

> *of their biography. Besides, they also ‘work on’ their biography much more unconsciously, for example by planning another holiday; by opting for a knee surgery; or by moving to another place of residence. In real life, there is no such thing as narrative foreclosure, but rather an ambiguous attempt to foreclose a certain biographical end in which people fear to lose their identity. All in all, we conclude that completed life is a euphemism, an indirect phrase with a pleasant sound, used to refer to an experience that is often felt as highly unpleasant. There is a considerable inconsistency between the meaning of the term and the meaning of the experience it refers to. The term can be seen as a frame, an image or metaphor that does not resonate with people’s lived experience. Using the term completed life might not only be inadequate and confusing. Fundamentally, it might be a reduction of the lived experiences to which the term refers.” (pp. 276-277).*

The Royal Dutch Medical Association (KNMG) concurs with that view (our translation):

> *“The concept ‘completed life’ has a positive connotation in the societal debate. In practice however it concerns vulnerable people who are lonely and feel they no longer matter. It is a complex and tragic issue for which there are no ready-made solutions.”*[35]

D.2. Empirical studies of the concept suffering in the context of euthanasia

First, we will discuss a number of empirical studies of the views held by physicians, nurses and laypeople of the acceptability of euthanasia depending on whether the suffering[36] is physical or non-physical.

Research has shown that many physicians and nurses, including the majority of people who don’t have a medical background, believe that euthanasia is justified in cases where people experience pain and *physical suffering* (see e.g. Cohen et al. 2006; Inghelbrecht et al. 2009). On the specific issue of the acceptability of euthanasia for *non-physical* suffering, Bert Broeckaert and colleagues conducted a study in 2006 in an attempt to chart the attitudes of Flemish palliative-care physicians on euthanasia and assisted suicide (Broeckaert et al. 2009). To the statement: “The scope of the law on euthanasia should be limited to euthanasia on the basis of unbearable physical suffering”, 55 % of the 147 respondents replied that they

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[35] KNMG, News 29 March 2017, see https://www.knmg.nl/actualiteit-opinie/nieuws/nieuwsbericht/knmg-voltooid-leven-wens-invoelbaar-maar-regeling-onwenselijk.htm.

[36] The authors of the studies used the terms physical suffering, psychological suffering …, and not ‘physical condition’, ‘psychological condition… In our discussion of these studies in this section of the opinion, we will stick with the terminology the researchers used.

disagreed and 26 % that they agreed (19 % abstained). In other words, *55 % of the Flemish palliative-care physicians surveyed in 2006 believed that the law should not be limited to unbearable physical suffering.*

A study Donald van Tol and colleagues conducted among Dutch general practitioners concluded as follows:

> *"Most doctors are only inclined to classify a patient's suffering as 'unbearable' when suffering is directly related to untreatable and actual pain or physical symptoms. Doctors' judgment of suffering varied strongly in cases in which physical symptoms are absent and a patient suffers from a combination of irreversible functional loss and 'existential' kinds of suffering. Although some doctors (17%) stick to the idea that physical symptoms are a necessary condition for 'unbearable suffering', a majority is willing to occasionally make an exception. When and for which case an individual doctor will make such an exception, is highly unpredictable."* (van Tol et al. 2010, p 166)

The literature on the views of the acceptability of euthanasia usually distinguishes between *paradigmatic or textbook cases* (cases deemed to be the least controversial by both clinicians and the general public), i.e. patients who are in pain and have serious physical symptoms, on the one hand, and *non-paradigmatic or borderline* cases, on the other hand. In the study by van Tol and colleagues, the following non-paradigmatic elements were put into vignettes (descriptions of situations of fictitious persons) to check GPs' views: the fear of future deterioration; major dependency; loss of dignity; loss of personal integrity (earl-stage dementia); tiredness of life; and considering oneself to be a burden to family and/or friends. From the description of the *case*, it was clear that none of the people had any physical symptoms or that the physical symptoms were under control. To the question "are you convinced that this is a situation of unbearable suffering?" 99 % of GPs replied yes when presented with the 'standard case' (54-year old woman with incurable metastatic breast cancer, suffering severe pain and nausea, bedridden, etc.). As to the case of major dependency 49 %; loss of dignity 48 %; considering oneself to be a burden to family and/or friends 35 %; fear of future deterioration 28 %; tiredness of life 18 %; and loss of personal integrity (early-stage dementia) 2 % (van Tol et al. 2010, p 168). On the basis of these figures, the researchers proposed the following analysis:

> *"The only exception in which some doctors seem to be less restrained than the law is the 'tired of living' case. In this case a medically classified diagnosis was absent, which excludes the possibility of lawful euthanasia. Yet almost 1 out of 5 respondents considered the patient's suffering in this case to be unbearable and would be willing to grant the patient's request. This could either mean that some doctors do not know the rulings on this point or that they do not agree with it."* (van Tol et al. 2010, p 171).

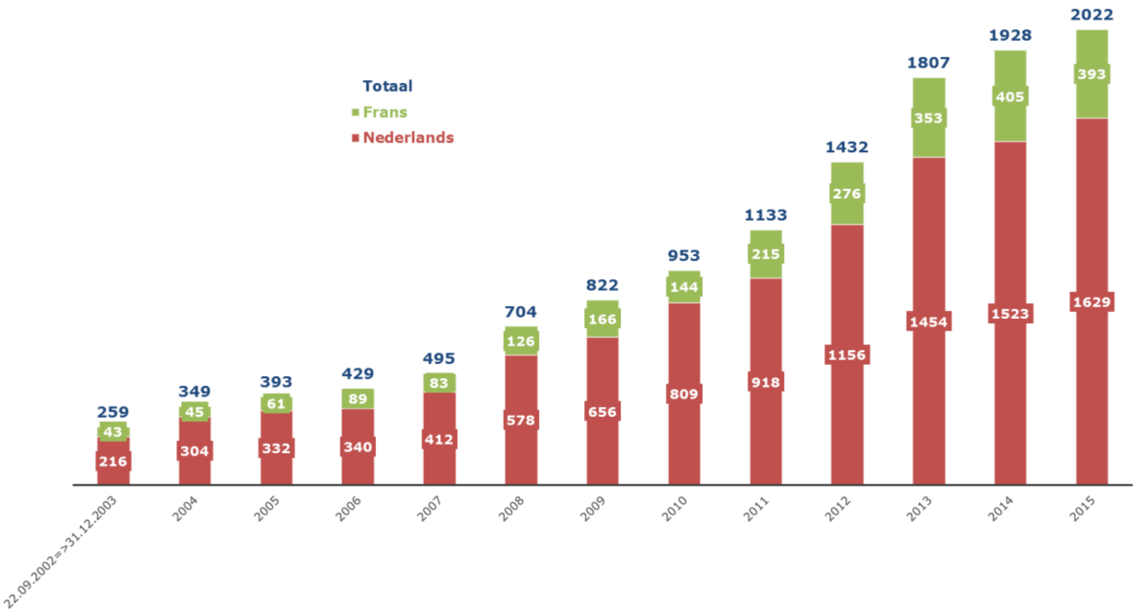
They drew the following conclusion from their research:

> *"This will concern both advocates and critics of euthanasia. Advocates might stress that some patients now may have to endure the unbearable possibly only because they addressed their request to the "wrong" doctor. Opponents of euthanasia on the other hand might stress the possibility of a slippery slope: if all boundary cases of unbearable suffering would lead to honoring the patient's request, the amount of euthanasia cases may rise significantly. What both sides will agree upon is that the issue where to draw the borderlines of 'unbearable suffering' is the Achilles heel of Dutch euthanasia practice and thus deserves ongoing attention" (van Tol et al. 2010, p 172).*[37]

D.3. Evolution of the number of euthanasia cases

Since the Act of 28 May 2002 and the declaration requirement came into effect, there has been an increase in the number of euthanasia declarations. It should be noted that there is year after year a big difference between de number of euthanasia declarations in Dutch (red) and French (green).

Aantal registraties en verdeling volgens taal



Source: Federal Control and Evaluation Commission on Euthanasia, "Seventh report to the legislative chambers, years 2014-2015", 2016, p 14.

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[37] See also a more recent study (based on a large-scale survey among Dutch GPs, physicians specialised in geriatric care, and clinical specialists) which produced highly similar results: Bolt et al. (2015).

The reports of the Federal Control and Evaluation Commission on Euthanasia (FCECE) - and more specifically the seventh report[38] - provide further information on the various categories of serious and incurable conditions that gave rise to the reported requests for euthanasia.

D.4. Flemish empirical studies of the evolution of the frequency of euthanasia

A recent empirical study by the research group "End-of-Life Care" (Association Research Group UGent-VUB) shows that, between 2007 and 2013, the *prevalence of euthanasia* increased across all patient groups and all care settings (see table 1 below) (Dierickx et al. 2015). There was a significant increase in both the number of *requests for euthanasia* (from 3.4 % of deaths in 2007 to 5.9 % of deaths in 2013) and in the percentage of *requests granted* (from 55.4 % to 76.7 %). The percentage of deaths from euthanasia rose from 1.9 % in 2007 to 4.6 % in 2013 (according to the FCECE reports this, on average, amounts to a nationwide increase of 0.44 % for the 2006-2007 period to 1.7 % for 2013[39]).

The *increase in euthanasia requests* is the largest in the group of people over the age of 80, who have a diploma of higher education or who were diagnosed with a cardiovascular condition. The *increase in requests granted* is the greatest among women, over the age of 80, people with a low level of education, and people who pass away in residential and care homes. In practice, these variables often occur in the same patients. On the specific issue of euthanasia and psychological suffering discussed in this section of the opinion, it must be pointed out that there was a marked increase in the numbers of euthanasia requests granted for 'other disease', a category which also includes psychological suffering.

The main reasons not to perform euthanasia were the fact that the patient had passed away already, had withdrawn his/her request or that the statutory requirements were not fulfilled. The percentage of cases where physicians stated to have denied a request from a patient for non-patient-related reasons (a restrictive policy at the care facility, personal objections, or fear of legal consequences) decreased dramatically (from 23.4 % in 2007 to 2 % in 2013).

Some members believe that it is essential that this debate is conducted in the light of the most recent scientific data on the (evolution of the) frequency of euthanasia and the trends in physicians granting euthanasia requests. This on the one hand because these data differ significantly from the data of the Federal Control and Evaluation Commission on Euthanasia

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[38] Federal Control and Evaluation Commission on Euthanasia, "Seventh report to the legislative chambers, years 2014-2015", 2016, 64 pp., http://overlegorganen.gezondheid.belgie.be/nl/documenten/fcee-euthanasie-verslag-2016.

[39] The seventh FCECE report 2014-2015 states 1.8 % in 2014 and in 2015 (p 19).

(FCECE), and on the other hand because these data show that there is a need for a debate on the interpretation of the Euthanasia Act.

Other members point out that the protocol for the studies of the frequency of medical end-of-life decisions allows for the argument that the concept of euthanasia, as worded in the survey physicians received, is a great deal broader than the legal definition in the Act of 28 May 2002, i.e. dispensing medication with the physician's intention to speed up death, without any further elaboration as to what is meant by speeding up death and what the medicines administered are. They would like to see that these studies use the legal definition of euthanasia.

The members who emphasise the relevance of these studies believe that the frequency studies do indeed demonstrate that there is major discrepancy between the numbers of reported euthanasia cases and the actual incidence of euthanasia. Admittedly, the lower euthanasia frequency in French-speaking Belgium does pull down the national figure and, of course, frequency studies are always estimates (the study's 95 % reliability interval indicates a minimum of 3 %). But, according to these same members, it can still be concluded that 1 euthanasia case in 3 is not reported.

Table 1: Euthanasia Requests and Granted Requests in Flanders, Belgium in 2007 and 2013[a]

	% of deaths with euthanasia request				% dying with euthanasia		% of euthanasia requests granted			
	2007	2013	2013 vs 2007		2007	2013	2007	2013	2013 vs 2007	
			Biv. *P* Value[b]	Relative risk (95% CI)[c]					Biv. *P* Value[b]	Relative risk (95% CI)[c]
Overall	3.4	5.9	<.001	1.7 (1.4-2.1)	1.9	4.6	55.4	76.7	<.001	1.4 (1.2-1.6)
Gender										
Male	3.6	5.9	.001	1.6 (1.2-2.2)	2.3	4.6	64.1	76.9	.006	1.2 (1.0-1.5)
Female	3.2	6.0	<.001	1.9 (1.4-2.5)	1.5	4.6	45.7	76.4	<.001	1.7 (1.3-2.2)
Age										
1-64	6.4	8.2	.23	1.3 (0.9-1.8)	3.9	5.6	61.9	68.1	.02	1.1 (0.8-1.4)
65-79	4.0	7.5	<.001	1.9 (1.4-2.6)	2.5	6.3	63.6	83.6	<.001	1.3 (1.0-1.7)
80 or older	2.0	4.6	<.001	2.2 (1.5-3.3)	0.8	3.4	38.1	75.4	<.001	2.0 (1.3-3.1)
Educational attainment										
None or primary	2.2	3.6	.05	1.7 (1.0-2.8)	0.8	2.5	35.1	69.5	<.001	2.0 (1.1-3.6)
Lower secondary	4.5	5.4	.52	1.2 (0.8-1.8)	3.0	3.8	65.7	69.7	.14	1.1 (0.8-1.4)
Higher secondary	4.4	7.5	.04	1.7 (1.1-2.7)	2.6	5.6	59.0	74.2	.17	1.3 (0.9-1.8)
College/University	4.5	12.9	.008	2.9 (1.4-6.1)	3.1	11.2	68.9	86.3	.11	1.3 (0.8-1.9)
Cause of death										
Cardiovascular disease (incl. CVA[d])	0.8	3.0	<.001	3.9 (1.4-10.9)	0.2	2.2	29.6	73.2	.04	2.5 (0.5-11.3)
Cancer	8.6	13.4	.001	1.6 (1.3-1.9)	5.6	10.4	64.4	77.5	<.001	1.2 (1.0-1.4)
Respiratory disease	1.6	2.4	.46	1.5 (0.5-4.4)	0.8	1.8	47.1	72.7	.28	1.5 (0.6-4.1)
Disease of the nervous system	4.2	6.3	.46	1.5 (0.6-3.9)	2.9	6.3	69.5	100	.05	1.4 (0.9-2.4)
Other disease	1.8	3.9	.009	2.1 (1.0-4.4)	0.3	2.7	18.8	70.7	<.001	3.8 (0.9-16.0)
Place of death										
At home	5.8	10.7	<.001	1.9 (1.4-2.4)	3.8	8.1	65.4	75.3	<.001	1.2 (1.0-1.4)
In hospital	2.8	5.0	.001	1.8 (1.2-2.5)	1.7	4.1	59.1	82.4	.009	1.4 (1.1-1.8)
In nursing home	2.1	3.9	.02	1.8 (1.1-3.2)	0.5	2.7	22.9	68.2	<.001	3.0 (1.3-6.9)
Other	3.4	1.1	.62	0.3 (0.0-3.1)	0.0	0.2	0.0	20.1	.40	-[e]

[a] Weighted percentages.

[b] Bivariate *P* Value based on Fisher's Exact Test.

[c] Relative risk is calculated with the complex samples function in SPSS 22.0.

[d] CVA = cerebrovascular accident.

[e] Relative risk could not be calculated for requests granted in other place of death.

D.5. Empirical studies of tiredness of life and euthanasia in Flanders and the Netherlands

D.5.1. Empirical studies of tiredness of life and euthanasia

Some members believe that one of the most interesting aspects the study by Dierickx et al. brings to light is that some Belgian physicians consider tiredness of life to be a legitimate reason for granting a euthanasia request (Dierickx et al. 2015). In this respect it must firstly be noted that the physicians surveyed could select multiple reasons why they would either or not grant a euthanasia request. 25.3 % of physicians stated that tiredness of life was a reason to grant a request, but it has to be said that this percentage also includes cases where tiredness of life was only one of several factors. In other words: we do not know in what percentage of cases tiredness of life was the *only reason*. Secondly, it must be pointed out that the researchers did not define the concept 'tiredness of life' in their study, in other words, that the interpretation of the concept itself was left to the physicians-respondents.[40]

In the Netherlands, some physicians seem to have performed euthanasia on patients who are tired of life. Mette Rurup and colleagues (Rurup et al. 2005) conducted a large-scale interview study among GPs, consultants and nursing home doctors (i.e. specialist palliative care facilities) on the frequency of requests for euthanasia and physician-assisted suicide in cases where there is no question of a serious condition. This study shows that, in the Netherlands, some 400 people a year ask for euthanasia or physician-assisted suicide because they are tired of life. In contrast to the aforesaid Belgian study, this interview study did provide respondents with a definition of 'tiredness of life' which read as follows:

> *"It does occur that patients do not want to continue living, whereas they do not have a severe physical or psychiatric disease. Sometimes this is referred to as suffering from life, being through with life or being tired of living. It is possible that the patient has health problems – e.g. a chronic illness or ailments of old age – it is also possible that the patient is healthy."* (Rurup et al. 2005, p 666)[41]

Thirty per cent of the physicians surveyed confirmed that they did receive requests of this nature at some stage during their career while 3 % confirmed that they already had granted a request in this type of situation. The requests GPs received mainly came from people living on their own and the over-80s. Their problems tended to be socially in nature, although 79 % of

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[40] **Some members** comment that the FCECE does not accept euthanasia declarations where the physician entered 'tiredness of life' in the text box 'exact diagnosis'. Physicians are always reminded that tiredness of life cannot be deemed to be a serious and incurable condition and are asked to state the serious and incurable condition the patient was suffering from.

[41] Also the Royal Dutch Medical Association, the *Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst* (KNMG), tried to define the term and opted for "suffering from life" (our translation): "suffering from the prospect of having to continue living without any or little quality of life, which gives rise to a persistent desire to die, while that lack of or poor quality of life cannot or is not largely attributed to a somatic or psychological condition". (KNMG 2004)

the people in question did suffer from one or more non-serious conditions such as arthritis, impaired vision, impaired hearing, digestive problems, etc. Most GPs turned down these requests, allegedly because there was no question of a serious condition or because the person's suffering did not pertain to the field of medicine. Half of the GPs suggested a different intervention which the patient usually refused.

D.5.2. Empirical studies of completed life

Els van Wijngaarden, researcher at the University of Humanistic Studies in Utrecht, conducted qualitative empirical research into the essence of "the lived experience of older people who consider their lives to be completed and no longer worth living (without evidence of a life-threatening disease or a psychiatric disorder)" (van Wijngaarden 2016b, p 278). She conducted in-depth interviews with 25 competent elderly people, 14 women and 11 men, who did not suffer from a terminal illness (or diagnosed) psychiatric disorder, aged between 67 and 99 years. While some did suffer from a series of age-related complaints, others still felt physically fit but were suffering from the prospect of such complaints. In her (phenomenological) research approach, the subjective experiential world takes centre stage: what is their lived experience and what is the common strand throughout the stories and experiences of these elderly people which causes them to say that they no longer believe their life is worth living? In her research she describes the essence of a "completed life" as follows:

> *"a tangle of inability and unwillingness to connect to one's actual life, characterised by a permanently lived tension: daily experiences seem incompatible with people's expectations of life and their idea of who they are. While feeling more and more disconnected to life, a yearning desire to end life is strenghtened." (van Wijngaarden 2016b, p 280).*

The experience of disconnectedness is recurrent in all stories, in the form of five constituents:

1. *a profound sense of existential loneliness: older people feel separated from others;*
2. *the pain of not mattering: they feel sidetracked;*
3. *the growing inability to express oneself: they are no longer able to carry out the activities they were committed to in life;*
4. *existential and physical fatigue: some are tired because of the physical age-related problems, but in many cases there is also an experience of existential weariness and boredom;*
5. *a sense of aversion to feared dependency. (van Wijngaarden 2016b, extracts from pp. 280-281).*

In her book *Voltooid leven: over leven en willen sterven* [Completed life: about life and wanting to die] (van Wijngaarden 2016a), she describes the substance of loneliness that came to the fore in all the stories as follows (our translation): "*As time goes on, they lose their connection and connectedness with others and with life itself. They feel isolated and left to their own devices.*" (p 25) *"They do long for meaningful contact but, at the same time, they are unable or unwilling to make the effort themselves."* (p 38)

The feeling of being irrelevant, of having been socially sidelined or written off, in sum, this loss of status, makes that their feeling of relevance, sense of purpose in life disappears (p 61). In a performance-driven society, social dignity and the perception of personal dignity is closely related to what one does in life (pp. 66-68). This feeling of a loss of dignity is confirmed by others. According to Els van Wijngaarden *"stories of meaninglessness in old age [...] cannot be disassociated from the way we look at and deal with old age and vulnerability."* (p 69, our translation)

The feeling that they are less and less able to show who they are (self-expression) causes these elderly people to lose their sense of identity (p 71). The ideal image of realisable identity is distorted: loss experiences, disappointment, ailments that come with old age, deterioration can lead to a damaged self-image (p 89).

These elderly people are tired because of their physical, age-related complaints and often also experience boredom and existential tiredness (p 93). A mere clinical approach or the medicalisation and psychologization of their existential tiredness (*"Aren't they just depressed?"* p 116, our translation) fuels their resistance because they do not recognise themselves in that image - narrowed down to a problem, a possible diagnosis (p 117). Furthermore, this psychopathological approach implies "*a tendency to regard the wish to die as a strictly personal matter"* (p 120, our translation). However, to fully understand this death wish, also social and cultural aspects such as *"loneliness, social isolation, marginalisation, social exclusion and stigmatisation"* must be acknowledged (p 120, our translation).

Finally, according to this study, these elderly people *"dread the thought of becoming dependent on others and of handing over the reins, while they are unsure whether or not their interests will be looked after properly (...) they relate a deep sense of shame and revulsion at their own deteriorating body and the dependence that comes with it"* (p 123, our translation). On the one hand, there is the issue of the vulnerabilities that come with old age, known as inherent vulnerability, and, on the other hand, there is a question of situational vulnerability which relates to the manner in which the world around you is organised, to sociopolitical choices, which is where the question for society lies: *"How do we want to deal with situational vulnerability and dependency? What do we, as a society, want to do to reduce these* *vulnerabilities? Do we invest or cut spending? What if vulnerability and dependency would be less of a stigma? How would that impact on the wish to die?"* (p 146, our translation).

D.6. Ethical debate

D.6.1. Implications (for the euthanasia request) of the refusal of treatment

Does a patient who refuses treatment preclude himself/herself from the option of euthanasia?[42] Under the Patient Rights Act, patients are always free to refuse treatment. However, the question is whether a patient who refuses to be treated for his/her condition still meets the statutory requirements of a serious and incurable illness and a medically hopeless situation. It is clear that a patient is entitled to refuse an experimental therapy and still retains the right to ask for euthanasia. He/she is also free to refuse a proposed treatment that will not benefit his/her health in any way. But, what if he/she refuses a therapy that would be beneficial or is considered to be beneficial to the patient's health? In psychiatry, where the therapeutic effects are often far more uncertain than in somatic medicine, that question is a particular sensitive one.

As stated above, the Netherlands Psychiatric Association issued a Directive on how to deal with requests for assisted suicide from patients suffering from a psychiatric disorder. This Directive also extensively deals with the issue of patients refusing the treatments proposed. In this Directive, more precisely the following point of view is expressed (our translation):

> *"Dilemmas can arise when a patient refuses a proposed treatment. [...] In the Committee's view, certain therapies can never be refused. That would in any case apply to all biological-psychiatric therapies in all indicated cases, on account of their generally relatively speedy effect and lack of serious side effects. However, the psychiatrist will have to ask himself how other, more drastic therapies he proposes, may affect the patient's suffering. Obviously an assessment of the chances, possibilities and probabilities is important here as there are no certainties. The next question the psychiatrist will have to ask himself/herself is whether the patient will perceive the potential improvement as worthwhile. Here values, standards and life purposes will come into play [...]. If the psychiatrist can reasonably assume that the patient will continue to experience his suffering as unbearable, the treatment refusal becomes acceptable. In cases such as these the refusal should not exclude assisted suicide.*

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[42] As regards the refusal to avail of the treatments proposed, some members observe that, in the context of the experts' testimonies to the Select Commission, they learned that some geriatric patients who ask for euthanasia do not find themselves in a medically hopeless situation but refuse whatever therapy the physician proposes and then claim that they find themselves in a medically hopeless situation.

> *Thus, in an individual case, the psychiatrist may come to the conclusion that the relationship between the burden on the patient and the expected results of the proposed treatment is unreasonable. One example would be a seriously traumatised, rapidly disintegrating patient who has been admitted on numerous occasions, has proven to be psychopharmacologically resistant and now refuses a new long-term clinical treatment in a first-class hospital. If the therapies were administered in accordance with the state of the art, the refusal to accept the treatment should not preclude the patient from assisted suicide.*"[43]

Incidentally, much store is put by this Directive. Although it was in first instance compiled for psychiatrists, the Regional Review Committees report the following:

> *"At a meeting with the permanent parliamentary committee in November 2014, the Minister of Health, Welfare and Sport indicated a desire to have the guidelines of the National* [Netherlands] *Psychiatry Association (NVVP) declared applicable to all physicians" (Regional Euthanasia Review Committees, Annual Report 2014, p 8).*

Within the Belgian Advisory Committee on Bioethics, there is a **consensus** (1) that it is the physician's responsibility to decide whether a serious condition caused by accident or illness is incurable and (2) that, conversely, the decision whether or not the physical or psychological suffering is constant and unbearable rests with the patient. To establish whether a patient finds himself/herself in a medically hopeless situation, the law also refers to the condition that the 'suffering cannot be alleviated'. Opinions differ on how that condition ought to be interpreted: who ultimately decides whether or not the suffering can be alleviated, the physician or the patient? **Some members** believe that a clear distinction must be made between the 'unbearable' and 'unalleviable' nature of the suffering: while the (un)bearability of the suffering is a subjective parameter, the (un)alleviable nature of the suffering is an objective one. **Other members** believe that these two aspects of suffering are intrinsically linked. Especially in concrete situations of psychiatric disorders, discussion arises whether or not a patient's suffering can be alleviated.

D.6.1.1.The physician is responsible for the final decision as to whether or not a patient's suffering can be alleviated

The members who emphasise that the aspect 'unbearability' of the suffering is a subjective parameter while the aspect 'unalleviable nature' of the suffering is an objective parameter argue that a patient's situation can only be qualified as medically hopeless if the patient has received all the therapies that have been proven to be effective in accordance with the state of

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[43] Netherlands Psychiatric Association, Assisted Suicide Committee (2009), Directive "Dealing with requests for assisted suicide from patients with a psychiatric disorder", pp. 39-40.

the art. The physician must explain and discuss this to/with the patient but is not entitled to delegate the responsibility for interpreting the statutory criterion that the suffering must be unalleviable to the patient. After all, it takes medical expertise to assess whether suffering *resulting from a condition caused by accident or illness* can be alleviated or not. The members in question believe that both the assessment of the seriousness and incurability of the condition caused by accident or illness and the review of whether a patient's suffering can be alleviated or not, are medical, objective matters. That goes for both physical and psychological suffering.

In matters of psychiatric disorders, they specifically refer to the cascade as provided in the Directive of the Netherlands Psychiatric Association: until such time as all indicated biological and psychotherapeutic treatments and social interventions that can ease the suffering have been resorted to, a patient cannot be deemed untreatable. Where a patient refuses a state-of-the-art treatment algorithm, for instance a patient suffering from depression who refuses electroconvulsive therapy, the statutory requirements have not been met, with the result that euthanasia is not an option. Of course, each patient can refuse a treatment proposal that is not in accordance with the state of the art.

These members also comment that therapy resistance in a patient suffering from a psychiatric disorder does not necessarily mean that the patient finds himself in a medically hopeless situation: the condition of some patients has been known to mysteriously improve over time. Doctors continue to follow up their patients and can present them with treatment proposals.

These members also believe that the procedure that facilitates euthanasia for a psychiatric disorder is all too easy: three physicians, only one of whom needs to be psychiatrist, can, as the law currently stands, decide whether a patient meets the statutory euthanasia criteria. If one compares this to the stringent criteria and procedure operated in the field of psychosurgery,[44] the members concerned wonder whether the statutory criteria for euthanasia actually provide the necessary due care guarantees. These members would like to see that the criteria and procedures for treatments such as these would also be adhered to for euthanasia requests.

Some of these members worry about a trend where some Belgian commentators are all too willing to leave the decision about the medically hopeless nature of a condition to the patient.

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[44] According to **these members**, serious questions can be asked about the fact that, in our country, the conditions for euthanasia are vaguer and more open to interpretation than the conditions operated for the most drastic though extremely rare psychiatric treatments: the psychosurgical procedure of deep brain stimulation. Someone suffering from a serious, incurable psychiatric disorder will only qualify for deep brain stimulation if a committee of experts has ruled that the diagnosis is correct and that a whole list of properly researched treatments have been tried already. This list was carefully compiled by a panel of experts and is scientifically underpinned. This is a concrete and objective interpretation of the criterion 'medically hopeless'.

They refer to an academic article on euthanasia requests from 100 psychiatric patients, published in 2015, where the procedure used was explained as follows:[45]

> *"There must be a thorough evaluation through multiple consultations regarding the specific determinants and conditions of 'unbearable and untreatable mental suffering' in each case. LT ascertained the psychiatric diagnoses, mental state and history of each patient after consultation with the treating practitioner(s), and made a thorough review of the case file and full psychiatric evaluation of the patient.*
> *All therapeutic options that could alleviate suffering, including palliative care, must be discussed with the patients and their practitioners. For these discussions, LT used the following NVvP [Netherlands Psychiatric Association] guidelines about these therapeutic options: (a) the therapy must offer a real prospect of improvement, (b) it must be possible to administer adequate treatment within a reasonable period of time and (c) there must be a reasonable balance between the expected results and the treatment burden for the patient.*
> *All procedural aspects should be explained to, and discussed with, the patient. Only when the patient repeatedly expresses the wish to die, and the patient's physician or psychiatrist indicates that the patient's reasons for this wish are sufficiently tangible and reasonable, will the formal request for euthanasia be filed and the planning begin. [...]"* (Thienpont et al. 2015)[46]

Even though this article does refer to the Directive of the Netherlands Psychiatric Association, *these members believe that the procedure that is followed significantly deviates from the Directive in question* since there is a major difference between:

- on the one hand, **discussing** "all the therapeutic options that could alleviate suffering" **with the patient** and, only if the patient continues to reiterate the euthanasia request, coming to the conclusion that the patient's reasons are tangible and reasonable (the procedure described by Thienpont et al.); and

- on the other hand, not qualifying a patient as untreatable "until all the following interventions have been **tried**: all indicated regular biological therapies; all indicated psychotherapeutic therapies; social interventions that can alleviate the suffering" (the procedure prescribed by the Netherlands Psychiatric Association, see above)

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[45] **These members** also believe that this initiative to transparently publish the manner in which euthanasia requests are evaluated in practice should be applauded.

[46] A fourth aspect, i.e. contacting family members if the patient asks for it, is also mentioned but is irrelevant in this context.

According to these members, quotes from the book by L. Thienpont "Libera me"[47], clearly illustrate this important difference in nuance:

> *"The lengthy, exhausting search makes that, for some patients, another test or new treatment proposal comes too late. They are done fighting. Then you could end up with a problem if the patient, because of the lengthy period of time, has become so demoralised that he or she can no longer be motivated to try the new therapy which, according to the state of the art, could offer him the prospect of improvement or recovery." (p 53, our translation)*

And:

> *"There comes a time when we have to admit that we are unable to help improve someone's quality of life, either because all the therapies have been exhausted or because the patient no longer wants to entertain another treatment proposal." (p 54, our translation)*

These same members also believe that a passage in the sixth Federal Control and Evaluation Commission on Euthanasia (FCECE) report 2012-2013 seems to suggest that, in practice, it is ultimately the patient who is allowed to decide that his suffering cannot be alleviated:

> *"In some cases, treatment was refused, which was discussed at commission level. The following consensus was reached: the option of euthanasia remains on the table provided the refusal to avail of treatment relates to a non-curative therapy or a therapy that has serious side effects."* (p 15)
> *"As regards the question whether the suffering can be alleviated or not, the patient's right to refuse pain treatment or even palliative care must be taken into account, e.g.* ***if the treatment in question would give rise to side effects or involve methods the patient would consider unbearable.*** *" (p 55, emphasis added, our translation).*

These members believe that this latter sentence in bold print is open to interpretation and, hence, far too permissive. If the sentence read "if the treatment in question would give rise to side effects the patient considers unbearable", it would be clear that the patient did already try the treatment as side effects only come to light during treatment. According to these members, the above sentence might suggest that a severely depressed patient who never received electroconvulsive therapy and point blank refuses to undergo this therapy would qualify for euthanasia anyhow. They believe it could suggest that a patient whose suffering could not be alleviated with a first antidepressant and refuses to try a second antidepressant

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[47] *Libera me. On euthanasia and psychological suffering: twelve years of talking to patients asking for euthanasia because of unbearable and prospectless psychological suffering; testimonies and reflections*, Lieve Thienpont, Witsand Uitgevers, 2015, 263 pp.

might find a doctor prepared to perform euthanasia. The addition of "or methods" in that sentence suggests, according to these members, that the patient would indeed qualify for euthanasia. The members concerned give preference to the afore-quoted stricter wording of the directive of the Netherlands Psychiatric Association.

These members are of the opinion that physicians must assume their clinical and ethical responsibility instead of leaving that to the patient. The latter modus operandi might even allow them to address any ethical concerns in their own minds with the argument "that is what the patient wants, who am I to go against that?". However, according to these members, it is simplistic and undesirable if doctors start delegating their clinical and ethical responsibility in the name of a unilateral interpretation of self-determination in this manner. Leaving the final decision on the medical hopelessness to the patient, even if all reasonable treatments have not been tried, would, according to the members in question, fuel the negative reactions from and discussions with family members that could arise in the wake of a euthanasia procedure. Discussions such as these regularly make it into the national and even the international papers[48].

D.6.1.2.The physician is responsible for deciding whether the condition is (in)curable, the patient has the final say as to whether the suffering is unbearable, and the (non-)alleviable nature of the suffering is determined on the basis of an in-depth and continuous dialogue between the patient and his physician.

Other members point out that a therapeutic proposal and/or medical solution to alleviate suffering does not give physicians the authority to decide whether or not the suffering is unbearable. In the end, that is the patient's decision to make but always in the context of continuous and open dialogue with his doctor. To the extent that the suffering is closely related to the underlying condition and the treatment for the condition in question, these members believe that the issue of suffering can never be completely disassociated from the therapeutic decision, whether by the physician or the patient. And vice versa, when decisions are taken about treatments that are based on scientific evidence, the suffering they cause will, one way or another, always be taken into consideration. Physicians take their decisions in consultation with others or after careful personal consideration and will always try to strike a balance between the hoped-for benefits of the treatments and the suffering they cause. It is

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[48] See, for one, the article in *The New Yorker*: Aviv, Rachel 2015. "The Death Treatment. Why should people with a non-terminal illness be helped to die?" in The New Yorker, June 22, 2015: (http://www.newyorker.com/magazine/2015/06/22/the-death-treatment).

Other members want to point out that one has to be very careful when quoting criticism in the foreign press. At the start of this opinion, it was indeed stated that one must be careful of mediatizing some cases that are not adequately documented.

about this latter aspect that the patient does have a say. More often than not, patients are given a say in the therapeutic decisions affecting them, because they want to prevent current and/or future suffering, for instance because they are no stranger to suffering. This is also the reason why patients are allowed to refuse a treatment, in many cases, another one in a long list of many. This is a refusal physicians can understand perfectly well and does not *a priori* lead to the presumption that it stems from some kind of irrational reflex on the part of the patient. In other words, these members are at one about the fact that it is the physician who must decide whether the illness is incurable or not. On the other hand, they find it extremely important that dialogue is pursued with any patient who asks for euthanasia. During that dialogue, maximum empathy with the patient's suffering is essential.

These particular members are of the opinion that the foregoing does not in any way suggest that the assessment of the unalleviable nature of the suffering is left to the patient. It goes without saying that only physicians have the relevant knowledge to medically alleviate suffering. However, they do emphasise the importance of dialogue between doctor and patient. Suffering is by definition subjective and the unbearable nature of that suffering is closely related to the fact that it is constant, which causes the patient to qualify this suffering as hopeless and unalleviable[49]. The patient's perception of the alleviable or unalleviable nature of the suffering is shaped by the dialogue with his physician, in the course of which the latter will discuss the possible solutions with the patient.

These members insist that, according to the Netherlands Psychiatric Association, a patient's refusal to sign up for an umpteenth treatment - where there is nothing to indicate that this refusal is not completely objective - does not detract from the patient's right to ask for euthanasia. The patients in question have proven to be "psychopharmacologically resistant" and have been treated psychotherapeutically *several times*. Hence, what is relevant in cases like these is not the "objectivity of the treatment" but the accumulated extent of the suffering a physician, as a human being, will be able to understand and which the physician will prioritise over the armoury of therapeutic treatments, an armoury which some believe to be infinite, especially in the field of psychiatry. These members believe that this type of medical stance should not simply be qualified as a delegation of that physician's responsibilities but as proof of that physician's humility in aid of his patient's human dignity. To them, this clear willingness to listen forms an integral part of a doctor's dialogue with his patient and is even the main reason for that dialogue.

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[49] It is sometimes difficult to classify the suffering of a person from a medical point of view and on the basis of purely medical criteria. The doctors who have to respond to certain requests are no more or less qualified than other people to assess the 'existential' quality of life of patients. They might humbly ask themselves: "Who am I to determine which life is worthy of living and to assess the admissibility of such a request?" It is difficult to answer this question when it comes to physical or psychological suffering, or even a combination of the two, while this is part of the medical profession and expertise. What then should be said when it comes to existential suffering, which is essentially not measurable?

D.6.2. The tiredness-of-life debate

The tiredness-of-life issue (i.e. cases where a person's desire to die does not stem from a medical situation but from the fact that the person in question feels that his/her life is completed and is tired of life, is extremely relevant in the context of this opinion because tiredness of life can unquestionably be associated with psychological suffering and that suffering can be persistent and unbearable. Thus, the question arises whether this tiredness of life is a form of psychological suffering within the meaning of this concept as used in the Belgian Euthanasia Act.

D.6.2.1. The debate in the Netherlands: the Brongersma case (2002) and the 'completed life' opinion (2016)

Reason why the **Dutch euthanasia and tiredness-of-life debate** is discussed in this opinion is the fact that this matter has provided food for thought in the Netherlands for several years now and regularly keeps cropping up in the societal debate.

The first reference to the concept 'tiredness of life' can be found in the Brongersma case[50], called after a former Dutch politician who passed away by assisted suicide in 1998. His attending physician, Dr Sutorius, justified his assistance in the suicide on the basis of the tiredness-of-life argument.

The Supreme Court of the Netherlands concluded this case on 24 December 2002, rejecting Dr Sutorius's appeal, stating that he could not invoke a case of force majeure in the absence of an indication of a medical condition.

In de context of this opinion, the main aspect of the judgment of the highest Dutch court is the fact that the Supreme Court ruled that euthanasia can be lawful only if the person's suffering is caused by *"medically classified somatic or psychological illnesses and conditions"*[51].

In the Netherlands, the debate is raging again. Dutch Parliament is discussing the issue of assisted suicide for people who feel that their life has been completed. On 4 February 2016, an advisory committee chaired by Professor Schnabel – i.e. the Advisory Committee

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[50] Hoge Raad (Supreme Court of the Netherlands), 24 December 2002.

[51] The Court quoted the following crucial passages from the preparatory debates for the Dutch Euthanasia Act (our translation):
"[The term] "completed life"... usually refers to people who tend to have reached a ripe old age and who, medically speaking, do not suffer from an untreatable illness or condition that causes them unspeakable suffering, and who have decided for themselves that the value of their life has deteriorated to such an extent that they prefer death to life. ... This bill does not aim to regulate this situation. ... We deliberately do not take the view that anyone who has lost the lust for life should also have the option to terminate (have) life (terminated)." (Memorandum following the Report, Parliamentary Papers II 1999-2000, 26691, no. 6, p 30).
"Society should heed such signals which may mask a cry for attention or help." (Minister for Justice Korthals during a legislative deliberation of the Standing Committees for Justice, Health, Welfare and Sport on 30 October 2000, Parliamentary Papers II 2000-2001, 26691, no. 22, pp. 59-60).
"After all, this bill does not extend beyond situations where a physician can form an opinion of the suffering on the basis of his medical expertise."(Minister for Health, Welfare and Sport Borst-Eilers, Proceedings II 23 November 2000, TK 27-2254).

"Completed Life" - produced a detailed report on the matter.[52] The Advisory committee in question distinguishes four situations of 'completed life' (p 12):

"1. Situations that already come within the current scope of the WTL (Termination of Life on Request and Assisted Suicide Act", i.e. cases where the suffering is by and large caused by a medical condition; the opinion does not relate to this;
2. Situations deemed to be 'borderline' because it is less obvious that the suffering is predominantly caused by a medical condition;
3. Situations where the suffering is not caused by a medical condition;
4. Situations where there is no [not even a] question of suffering."

To the question whether the WTL ought to be amended to cater for 'completed life' situations, the Advisory committee replied that the WTL does not need to be amended:

> *"(...) [Th]e WTL is working well and is (...) implemented with due care. It is also clear that the WTL, on account of its general formulation of the due care criteria, offers plenty of scope already. The current interpretation - as advocated by the RTEs (Regional Euthanasia Review Committees) and the KNMG [Royal Dutch Medical Association] – is that a plethora of age-related complaints can be the cause of hopeless and unbearable suffering within the meaning of the WTL. However, the suffering must predominantly have a medical cause. The person does not have to suffer from a serious (life-threatening) medical condition."* (p 215, our translation)

The Advisory Committee "Completed Life" concluded that "*in its current form, the WTL offers sufficient scope for the majority of people whose suffering is proportionate to the perception that their life is 'completed' and who can be included"* in the second category. It does not offer that scope for the situations described in categories three and four (pp. 230-231, our translation).

However, the Advisory Committee's conclusion triggered a new polemic which, in October 2016, gave rise to a Government's response[53] from the Minister for Health, Welfare and Sport, Mrs Schippers, and Mr Van der Steur, Minister for Security and Justice. In their letter, they mention the provision of a separate legal framework for assisted suicide - i.e. separate from the existing WTL or Termination of Life on Request Act - for people who consider their life completed and find themselves in situations 3 or 4 of the report of the Advisory Committee

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[52] Adviescommissie voltooid leven [Advisory Committee Completed Life]. "Voltooid leven. Over hulp bij zelfdoding aan mensen die hun leven voltooid achten [Completed life. On assisted suicide for people who consider their life completed]", The Hague, January 2016, 233 pp., published at: https://www.rijksoverheid.nl/onderwerpen/levenseinde-en-euthanasie/documenten/rapporten/2016/02/04/rapport-adviescommissie-voltooid-leven

[53] See https://rijksoverheid.nl/actueel/nieuws/2016/10/12/kabinet-ruimte-voor-hulp-bij-zelfdoding-bij-voltooid-leven.

"Completed Life".[54] On the one hand, the ministers argue that autonomy is "*obviously not an absolute value*", but, on the other hand, that *"where people no longer have any perspective in their lives, and, as a result, have developed a persistent, active wish to die […] the rationale behind the need to protect life is under pressure, because, to them, life is no longer worthwhile.*" (Letter from the Cabinet p 6, our translation).

But the Cabinet's proposal is also controversial in the Netherlands. The Royal Dutch Medical Association KNMG, for one, published the following statement[55] on 29 March 2017: *"To the medical profession it is understandable that people want to have certainty and peace of mind about their end of life, at that moment in time or for the future. But a separate 'completed life' Act alongside the current Euthanasia Act is fraught with risks and disadvantages and is, for that reason, undesirable."* To the KNMG, it is *"a social issue how we respectfully and appropriately deal with a situation where an elderly person experiences a sense of pointlessness and suffers from life"*. The medical association is worried that *"the introduction of a law such as this may lead to undesirable social effects such as feelings of insecurity among the elderly and the stigmatisation of old age. Instead of opening up another road to assisted suicide"* the KNMG deems it more appropriate to invest in *"more research to support other solutions than the course the Cabinet has chosen".* The KNMG also states that another law alongside the Euthanasia Act (WTL) would undermine the current careful practice of euthanasia. (our translations)

D.6.2.2. How much leeway for care providers to interpret the scope of the Euthanasia Act themselves?

The report of the Dutch Advisory Committee "Completed Life" (Schnabel) discusses the leeway for interpretation the Dutch Act gives practitioners. The Advisory Committee bases itself on a discussion of legal history, case law of the Dutch Supreme Court (inter alia the Brongersma case), the interpretation by the Regional Euthanasia Review Committees (RTEs) of the due care criteria set out in the WTL (see also the RTEs' Code of Practice, 2015) and the opinion of the Royal Dutch Medical Association, the *Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst*, (KNMG).

As far as the RTEs and the KNMG are concerned, the report more specifically states:

> "*The RTEs have – with reference to the Brongersma judgment and the legal history of the WTL – on the basis of their opinions and annual reports among other matters made it clear that they must examine, on a case-by-case basis,*

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[54] At the end 2016, also the Dutch political party D66 published a bill to facilitate assisted suicide as of the age of 75, see https://d66.nl/wet-voltooid-leven-pia-dijkstra/.

[55] KNMG, News, 29 March 2017, see https://www.knmg.nl/actualiteit-opinie/nieuws/nieuwsbericht/knmg-voltooid-leven-wens-invoelbaar-maar-regeling-onwenselijk.htm

> *whether the physician in question could reasonably have come to the conclusion that the hopeless and unbearable suffering was predominantly caused by (a) medically classifiable illness(es) or condition(s), i.e. (according to the RTEs) had a medical basis. Since there is no requirement that the medical condition must be serious (life-threatening), the RTEs deem that an accumulation of age-related complaints can be the cause of hopeless and unbearable suffering. In that scenario it is essential however that the unbearable and hopeless suffering is predominantly caused by a medical condition. Also the KNMG has taken the view that there must be a question of unbearable and hopeless suffering within the meaning of the WTL resulting from an accumulation of age-related complaints, including the loss of function, that lies at the origins of the progressive deterioration. According to the KNMG there must always be a medical basis, a condition that can be qualified as an illness or a combination of illnesses/complaints."* (pp. 182-183, our translation).

The conclusions and recommendations of the report by the Advisory Committee (Schnabel) illustrate the scope and the elasticity of the WTL:

> *"Critics (…) argue that the scope of the WTL is 'expanded' as time goes on. However the due care criteria set out in the WTL are worded broadly. (…) [Th]is [has] been a deliberate and substantiated choice on the part of the legislator, where the wish to leave scope for case-specific circumstances and future developments and insights took centre stage. Based on practice and changing insights and opinions in legal doctrine, the medical profession and society, the broadly worded due care criteria can be nuanced and further interpreted while allowing room for a mitigating interpretation of the due care criteria (…)*
> *The Advisory Committee considers it its task to point out that the leeway in the interpretation of the text of the WTL is not unlimited for changed/changing opinions and future developments".* (p 211, our translation)

Some similar elements can be found in Belgian law. One of the characteristics of **Belgian medical law** is that it resorts to offering a general framework that delineates the rights and obligations, without necessarily providing mandatory or restrictive definitions. It relies on concepts such as maximum autonomy and quality of life (Palliative Care Act), or dignity (Patient Rights Act art. 5. "Patients are entitled, with due regard for their human dignity and autonomy and without any distinction on whatever grounds, to a qualitative service from professional practitioners which is tailored to their needs", our translation). Article 12, §2 of the Patient Rights Act stipulates that minor patients can exercise these rights if "they can be deemed capable of a reasoned assessment of their interests" (our translation).

The Belgian legislator chose to delineate the Euthanasia Act by means of numerous adjectives and adverbs (e.g., the request must be voluntary, well-considered and repeated, and not the result of any external pressure; a serious and incurable disorder caused by accident or illness; medically hopeless situation; constant and unbearable physical or psychological suffering) and by describing a procedure, which does not mean that the legislative framework is hermetically sealed.

According to **some members**, the Belgian legislator's choice of general terms (which they deem the terms 'illness' and 'suffering' to be an example of) gives the actors in the field, the care providers and patients, the option to interpret the Act as they see fit and, in doing so, to assume their own responsibility. Fact is that society changes. According to these members, the terms of the 2017 debate are no longer the same as in 2002, the year the Euthanasia Act was adopted.

Other members believe however that it is clear from the preparatory debates for the Euthanasia Act that the legislator never intended to use vague terms but, to the contrary, chose to word the Act in such a way to clearly define who qualifies for euthanasia and who does not. Furthermore, these members believe that there are no indications to believe that the argument to the effect that the meanings of the terms of the debate would have changed since 2002 is a valid one. According to these members, the legislator's intention to clearly demarcate the Euthanasia Act is evident from the preparatory debates for the Act:
- During the plenary session of the Senate dd. 24 October 2001, Senator Paul Galand (Ecolo) replied as follows to the criticism that the scope of the bill was overly broad:

> *"The patient must suffer from a psychological illness, not from psychological despair. I am not one of the authors of the bill and I have my doubts about certain elements. However, I do believe that the text must be read as it was written. I note that some do not understand it, but the words must be read correctly. There must be a question of illness. As it happens, psychological despair is not an illness as such. One should not be misled by the expression 'psychological suffering'. Euthanasia is a medical act that is associated with an incurable illness. Any physician who ignores this illness-related framework and, hence, the medical diagnosis, can be prosecuted for a crime and is therefore punishable by law. As science stands today, the medical diagnosis must confirm that the illness is incurable and cannot be alleviated." (our translation)* [56]

- While the debates of the bill by the Committee Health were being debated in the Chamber of Representatives on 1 March 2002, the following was raised:

> *"The Parliamentary Committee Health unanimously deems that purely psychiatric suffering can never give rise to euthanasia. The subjective*

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[56] *Parl. Proc.* Senate 2001-02, no. 2-152, 40-41.

> *dimension of psychological suffering is too broad, and will open the door to abuse. It is next too impossible for a physician to assess the extent of psychological suffering; furthermore, the will of people who are mentally ill is often not unambiguous and will depend on the moment. Finally, in a case like this, all medical context is lacking. Depressed and psychiatric patients, people suffering from dementia or Alzheimer's cannot be included in the scope."*[57] *(our translation)*

- During the plenary session of the Chamber of 15 May 2002, Public Representative Georges Lenssens (Open VLD) stated as follows:

> *"Some of our members do have a problem with patients who are not terminally ill. It would have been easier for us too if the bill had been subdivided into an arrangement for terminally ill and an arrangement for non-terminally ill patients. We were mainly concerned about psychiatric patients and people suffering from dementia. From the proceedings in the Committees Justice and Health it is clear however that it was never the intention to apply the Act in question to these patients."*[58] *(our translation)*

According to these members this type of information from the preparatory debates for the Euthanasia Act is extremely relevant, *not* because they believe that requests for euthanasia from psychiatric patients must *a priori* be rejected but because this information (including any similar passages from the extensive preparatory debates) shows that, at the time the bill was voted on, this Act contained solid and clear guarantees as to the determination and demarcation of the type of situations where euthanasia could be an option.

The members in question stress that the Belgian Act leaves far less leeway for interpretation than the Dutch Act, in view of the major differences in the wording of art. 3(1) of the Belgian Act and the corresponding art. 2 of the Dutch Act, which merely stipulates that the suffering must be unbearable and medically hopeless, while the Belgian Act clearly contains more (and more specific) criteria.

As a result, these members are concerned about the following paragraphs in the sixth **Federal Control and Evaluation Commission on Euthanasia** (FCECE) report 2012-2013:

> *"In a number of rare cases of patients of a highly advanced age who were suffering from various diseases, some members of the commission believe that the suffering and the request for euthanasia tended to be associated with the natural consequences of these patients' age, not their diseases."* (p 15, our translation)

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[57] Euthanasia bill, *Parl. Docs.* Chamber 2001-02, no. 50, 1488/005, 9.

[58] *Parl. Proc.* Chamber 2001-02, Criv. 50, Plen 229, 93.

> *"The distinction that had to be made between elderly patients' suffering caused by illness and the suffering that is "normal" for that age at times gave rise to disputes between the majority of the commission and a number of its members."* (p 27, our translation)

The above quotes cause these members of the Advisory Committee on Bioethics to fear that *age may be qualified as a serious condition and, hence, as grounds for a legitimate euthanasia request*. This clearly does not tally with the legislator's intentions when euthanasia was decriminalised. These members consider that highly problematic.

Other members of the Advisory Committee on Bioethics do not have the same interpretation of the reports of the FCECE. In the seventh report of the FCECE, the following was also stressed with regard to polypathology and the elderly: *"This does not at all mean that the (FCECE) commission considers old age to be a disease. Old age and tiredness of life do not justify euthanasia in the absence of a serious and incurable disorder"* (our translation).[59] These members believe however that the FCECE never intended to equate ageing with a serious and incurable condition. They do believe that the essential conditions of the Act must obviously be examined in function of the ability of the person asking for euthanasia to adjust.

D.6.2.3. Proposal on how to clarify euthanasia requests on grounds of tiredness of life

Some members believe that an important contribution to the euthanasia and tiredness-of-life debate is made by an article that was published in the *Tijdschrift voor Geneeskunde* [Medical Journal] in 2016. In that article, a number of Flemish experts (from the Working Party 'Palliative care and Geriatrics (PaGe)' of the Federation Palliative Care Flanders) outlined the issue of tiredness of life and presented a practical tool ('flowchart') to thrash out these matters with patients. (Van Den Noortgate et al. 2016) These experts firstly state that they, as geriatrician, GP or Consultative and Coordinating Doctor - certainly in Flanders - are increasingly faced with requests for euthanasia for reasons of tiredness of life (p. 145). In their reflections, these experts base themselves on a clear definition: tiredness of life is described as "the psychological suffering of a person whose quality of life, owing to (a combination of) medical and/or non-medical factors, has deteriorated to such an extent that they would prefer death to life." (our translation)[60] According to this definition, the presence of suffering is an essential characteristic of tiredness of life. (p. 146)

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[59] See website of the FCECE: http://overlegorganen.gezondheid.belgie.be/nl/advies-en-overlegorgaan/commissies/federale-controle-en-evaluatiecommissie-euthanasie, publicatie, Zevende verslag (2016) aan de Wetgevende kamers met betrekking tot de jaren 2014-2015, p. 27 (our translation).

[60] Delbeke, E. "Hulp bij zelfdoding en levensmoeheid (Assisted Suicide and tiredness of life)" In: "Juridische aspecten van zorgverlening aan het levenseinde (Legal aspects of end-of-life care)". Mortsel: Published by Intersentia, 2012: 395-411.

In their analysis of the problem, the experts point out that suffering can have wide-ranging causes and dimensions, and is always an extremely personal matter, which, in turn, is also associated with the person's view of mankind and philosophy of life. This also means that there does not have to be a direct link between the source or the cause of the suffering and the way it is experienced. A second point of particular interest is the distinction that must be made between hopeless and unbearable suffering as the first is the subject of a professional opinion on the possible treatment and care perspective and is often objectifiable. The second criterion is in first instance considered to be a matter for the patient and will always be subjective and strictly personal. These experts claim that the assessment of the suffering and the offer of help to patients who find themselves in these circumstances pertain to the physician's professional, medical domain and believe that it is highly relevant and essential to avail of the help and expertise of other professional care providers (p. 146), all the more because tiredness of life is rarely the problem of the individual only but is often also a social problem, which calls for an in-depth societal and ethical debate rather than medicalisation (p. 153). Because, on the basis of the afore-quoted definition, tiredness of life refers to (a combination of) medical and/or non-medical factors, it is essential to examine them broadly, to explore the interactions between them and to address them where possible. "*Tiredness of life will come more to the fore in cases where the psychological suffering can predominantly be attributed to non-medical factors. Where medical factors play an important role and the non-medical factors hardly or not at all, the person may be tired of the illness, the treatment and/or the battle, but not necessarily of life. It is important to determine the relevance of each of these (medical and non-medical) factors that lie at the origins of that tiredness of life and to assess to what extent each one of them plays a part therein. After all, it is quite possible that a person suffering from a serious physical condition claims to be tired of life, not because of the underlying illness or treatment but because of a non-medical factor such as the feeling of uselessness or an acute financial problem. By not thrashing out this matter it is possible that the opportunity to alleviate a person's suffering is missed.*" (p. 147) The physical factors can be wide-ranging, but aside from the underlying medical condition 'frailty' (extreme vulnerability and reduced reserves that lead to increased dependence and death) can have an important impact on elderly people's quality of life. Among the psychological factors that need thrashing out - because these are the ones that contribute to the unbearable nature of the suffering in particular - are the psychiatric disorders (e.g. mild depression), but also the various coping strategies of patients and their environment, and factors like the degree of loneliness, the perception of dignity and responsibility, possible traumatic life experiences, the level of subjective well-being and the spiritual /existential sources of energy. Experience has taught us that socio-economic factors (poverty, level of education, etc.) are important risk factors for tiredness of life.

Because tiredness of life has not only become a theoretical but also a practical challenge in recent years, the authors propose a step-by-step approach[61] in their contribution. The first step consists of systematically exploring the tiredness of life (assessing the suffering), while paying sufficient attention to the non-medical factors. After all, psychological suffering caused by non-medical factors can be as severe if not more severe than psychological suffering caused by accident or illness, and calls for the intervention of other care providers such as a geriatric psychiatrist, a psychologist, a social worker or chaplain/counsellor. A second step will involve assessing the treatment options. Treatment may be possible and welcome. Literature teaches us that many patients have a negative attitude towards a therapeutic approach to their problem, with the result that although treatment may be possible, it may be dismissed. In the absence of a persistent request for euthanasia, early care planning should be considered. If the request is persistent however, step 3, i.e. an assessment of the statutory due care criteria for euthanasia can be proceeded to, as would be the case if a patient's condition was untreatable. Where, based on a professional opinion and experience, there is no question of unbearable suffering that cannot be alleviated or of an underlying medical condition (in which case the suffering must be the result of a serious and incurable disorder caused by accident or illness), which is also hopeless, the request does not come within the scope of the Euthanasia Act. But even in that case, the physician and/or his team are bound by a duty of care and will need to be mindful of the patient's wider well-being and, together with the other care providers, stand by him in his despair that nothing concrete can be 'done'.

In certain situations there is no consensus as to whether the due care criteria and the medical factors as underlying reason for the suffering and the request are fulfilled. When faced with a grey area such as this, the authors believe that a consultation process with colleagues, the team and an ethical opinion may be useful.

Other members take the view that this consultation process is an option, a tool a physician can avail of if he/she so wishes and in harmony with the patient.

Within the Committee there is no discussion about the fact that the Euthanasia Act requires a medical indication - even if the suffering is perceived to be unbearable - before euthanasia becomes an option. However, as to the definition of "medical indication", there is no consensus between the Committee members.

All the members believe that some forms of polypathology – i.e. the presence of several diseases - can constitute a medical basis for considering a euthanasia request on condition that the unbearable *and* medically hopeless *and* unalleviable nature of the patient's suffering *is caused* by the polypathology in question.

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[61] Reference flowchart: www.palliatief.be/publicaties_levensmoeheid

Some members fear that many interpret the term polypathology in a way that would imply that any person over the age of seventy meets that requirement[62].

To conclude, all members agree that, in the absence of a medical basis, euthanasia is not an option and that getting older is not an illness in itself. Within this consensus, the members of the Committee differ as to the degree of severity and incurability of the age-related polypathology.

D.6.3. Euthanasia and the medicalisation of social problems

Facilitating euthanasia as an answer to suffering without any underlying serious condition caused by accident or illness could fundamentally alter our view of medicine and society. To a certain degree, that trend is evident already since plenty of people believe that they are *entitled* to euthanasia, purely on the grounds that they perceive their suffering as constant and unbearable. No matter how sincere that belief may be, it completely disregards the fact that the Euthanasia Act only accords the right to *ask for* euthanasia and that the Act stipulates that, aside from the attending physician, a second (and in the case of patients who are not terminally ill also a third) physician must examine the patient and give his opinion as to whether all the statutory conditions (including the criteria listed under art. 3(1)) have been fulfilled. Physicians cannot be reduced to mere 'executors of euthanasia requests'.

It must be emphasised that the wording of art. 3(1) clearly indicates that the legislator never intended to facilitate euthanasia for anyone experiencing constant and unbearable suffering without an underlying pathology. Even in cases of unbearable suffering, there may be sound ethical reasons to refuse requests such as these. After all, granting these requests would open the door to an (extreme form of) *medicalisation* in areas where this would be completely unjustified.

Once could argue that **countless people who are tired of life, do have medical issues (e.g. traditional age-related ailments** such as arthritis, impaired vision, digestive problems). **The point, however, is that if the *mere presence* of this type of medical symptoms would be considered a good enough reason to meet the conditions of art. 3(1), one might argue that *every* senior citizen could qualify for euthanasia**. Everyone who reaches a certain age will at one time or another be affected by a series of physical complaints and most of us don't even have to wait for those until we turn 70 or 80 years of age. This would *completely*

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[62] Raus, Kasper; Sterckx, Sigrid; Beyen, Anne; De Lepeleire, Jan; Desmet, Marc; Devisch, Ignaas; Focquaert, Farah; Ghijsebrechts, Gert; Haekens, An; Huysmans, Gert; Lisaerde, Jo; Mullie, Senne; Provoost, Veerle; Ravelingien, An; Schotsmans, Paul; Vandenberghe, Joris; Van Den Noortgate, Nele; Vanden Berghe, Paul, Vanderhaegen, Bert, "Komt nagenoeg iedereen van boven de 70 jaar nu in aanmerking voor euthanasia? [Does just about everyone over the age of 70 qualify for euthanasia now?]", *Knack*, 15 November 2016: http://www.knack.be/nieuws/belgie/komt-nagenoeg-iedereen-van-boven-de-70-jaar-nu-in-aanmerking-voor-euthanasie/article-opinion-776597.html.

undermine the legislator's intentions. The law stipulates that the unbearable suffering must be *caused by* a condition which, in turn, must be *the result of* accident or illness. Even though the suffering of many people is unquestionably caused by a combination of psychosocial and medical problems, it is the *medical problems* that must be the cause of the constant and unbearable suffering. Psychosocial problems are not medical problems. Loneliness, for one, is not a medical problem, with the result that we should in all honesty ask ourselves why it should be a physician's task to resolve matters such as these.

If we were to equate suffering from psychosocial problems to a medical issue, we run the risk of ignoring the real tragedy and of not asking ourselves *why these people experience this type of suffering*. Suffering such as this is often caused by social indifference, which leads to isolation and alienation, and, in turn, results in sincere feelings of loneliness, abandonment and uselessness. These widespread *social* problems urgently require a social, economic and political answer, *not* a medical answer and most certainly not one in the form of euthanasia.

The efforts we, as a society make, to tackle social isolation and alienation, to provide adequate care to prevent and treat psychiatric and other forms of psychological suffering, the resources we set aside for them, are grossly inadequate. Our current failure to sort out these problems cannot be used as an argument to facilitate euthanasia for people who find themselves in a situation like this. Facilitating euthanasia as an answer to suffering *without the presence of a serious and incurable disorder caused by accident or illness* would boil down to the worst form of *medicalisation of socio-economic problems* imaginable.

This *by no means* entails that people who are suffering unbearably and constantly but whose suffering is not caused by a serious and incurable disorder caused by accident or illness should be left to their own devices. What is does mean is that the people in question do, by law, not qualify for euthanasia. Not because their type of suffering is not constant and unbearable (which it undoubtedly often is). Not because they cannot be deemed legally competent and ability of discernment (autonomous) (which they often are), but simply because ability of discernment is only one of the many (legal and ethical) criteria to qualify for euthanasia.

Some members emphasise that the legislator had the clear intention that euthanasia would remain a last-resort option, whether the suffering is physical or psychological in nature. In an article published in 2015, American bio-ethicists Barron Lerner and Arthur Caplan wondered whether the practice of euthanasia in Belgium and the Netherlands wasn't on the slippery slope (Lerner & Caplan 2015). One of the issues they worried about was the fact that a study of the Dutch End-of-life Clinic showed that loneliness was often raised as grounds to ask for euthanasia. Lerner and Caplan comment as follows: *"Loneliness, even if accompanied* *by other symptoms, hardly seems a condition best addressed by offering death."* (p 1640) They also wondered whether the increase in the number of euthanasia cases is reminiscent of some form of *"carte blanche acquiescence among physicians to the concept of patient self-determination"* (ibid., p 1641). **These members believe that these questions, which are rarely or no longer posed in Belgium, are highly relevant.**

However, those same members also wish to emphasise that their criticism and concerns do not mean that euthanasia for psychological suffering should be abolished outright. What it does mean is that euthanasia should be a last-resort option as the legislator intended it to be, **that all the conditions listed in art. 3(1) of the Act must be rigorously applied, that compliance with these and any other statutory requirements must be strictly monitored, and that a number of aspects of the Act itself need to be fine-tuned**. This brings us to the specific recommendations we wish to formulate.

Other members hold a more radical view and are of the opinion that euthanasia should be made legally impossible when asked for a psychiatric disorder that does not stem from a demonstrable, irreversible physical tissue injury should be made legally impossible. To the extent that the Euthanasia Act does not provide any clarity on that particular point, a legislative amendment is called for to ensure that euthanasia on the above grounds is no longer decriminalised. In the case of psychiatric disorders, these members argue that it is impossible to unambiguously and objectively differentiate an autonomous request for euthanasia from a wish to die triggered by the pathology in question. The loss of autonomy - caused by a distorted sense of reality, serious mood disorders or delusions – is inherent to psychological suffering. This is precisely why this type of suffering is so severe and is often experienced as hopeless and, hence, unbearable.
It can never be conclusively established that conditions such as these are untreatable because, in time, improvement may be possible.

According to those who embrace this point of view, a unilateral emphasis on autonomy does not factor in the intrinsically relational component of psychiatric disorders or the impact of mechanisms like projection, transference and countertransference. Leaving room for a euthanasia request in the therapeutic relationship could pave the way for a possible dynamic of suicidal thoughts which would all too often drive a psychiatric patient towards euthanasia and could have a negative impact on psychiatric care itself, not only in terms of the individual patient, but also in terms of the wider care environment these patients have often been admitted to, not uncommonly for extended periods of time.

The members who did not see the need or deem it opportune to elaborate on the definition of suffering, whether physical or psychological, alleviable or not, and,

accordingly, who do not believe that the Euthanasia Act of 28 May 2002 should be amended for psychological suffering, are wondering about the rationale behind this point of view. Should that point of view, adopted in the media by those who are opposed to euthanasia, be interpreted as a desire to automatically preclude every psychiatric patient from the Euthanasia Act? What do the words "irreversible and demonstrable tissue injury" mean?

In support of that point of view, the latter members consider that a train of axioms are bandied about:

- the impossibility to differentiate between an autonomous request for euthanasia and a death wish prompted by the pathology;
- the impossibility to give an opinion on the incurable nature of the psychiatric disorder;
- the triggering of suicidal thoughts as a result of the request for euthanasia having been approved (sic);
- the possibility of 'infecting' other patients.

To these members this train of unsubstantiated assertions is rather peculiar. Not every psychiatric disorder can be cured. It is possible that a paranoid patient, by the nature of his/her condition, precludes himself from the option of euthanasia[63]. But that is not the case for each patient suffering from a psychiatric disorder. And health professionals are quite capable of differentiating between a voluntary, repeated request for euthanasia made without any external pressure and a wish to die prompted by the disorder itself. As regards the concept 'example to other patients', that argument was already raised with regard to Alzheimer's and Hugo Claus's euthanasia. In that argument it is always forgotten that a request for euthanasia is a personal matter and does not imply that every patient who ends up in a situation like this will ask for euthanasia!

Furthermore, the autonomy issue in the euthanasia procedures should not be approached in an abstract manner. That autonomy can only be validly exercised if the patient has access to the relevant information, and his/her request was discussed, negotiated and considered with the attending physician or where necessary, physicians, the medical team and his/her nearest and dearest. Euthanasia is a shared decision, a decision that respects a person's right to autonomy.

Finally, according to these members, there is a clear advantage to be gained from not automatically excluding psychiatric patients from the scope of the Euthanasia Act. Thanks to the dialogue that is created, thanks to the time one takes, some requests become less acute.

Some members believe that it is scientifically flawed to claim that psychiatric disorders are

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[63] Bulletin ADMD, nr 140, 2' trimester 2016, pp. 5-8. « *Euthanasie et psychiatrie, le grand malentendu. Conférence de Bea Verbeeck, psychiatre, leif-arts, Ulteam* », p. 7, our translation : "*What about the patient with paranoid delirium, with or without hallucinations, who makes him suffer martyrdom but refuses any drug treatment out of fear that it might poison him? It is obvious that the patient is suffering, and that the degree of his suffering can be insurmountable. But what about his capacity of discernment? For my part, his application will not be admissible, but perhaps it is debatable!*"

not coupled with structural changes in various brain structures. Certainly in the chronic forms irreversible changes take place.

E. Conclusions and Recommendations

E.1 Question 1: Does the legal basis to obtain euthanasia vary in cases where also the partner's request for euthanasia can be granted?

In her oral question to Minister Onkelinx, Senator Elke Sleurs referred to a mediatised euthanasia case where a couple applied for euthanasia. The Committee points out that whether it concerns a couple, married or not, is irrelevant here. Each request is unique, must be examined on its own merit and must meet the legal requirements, like any other request for euthanasia. The fact that it concerned a couple, married or not, is irrelevant to the examination of the conditions the legislator laid down. If the partner's situation does not meet the statutory euthanasia requirements, then there is no legal basis to grant the euthanasia request.

The Committee understands the anxiety of the surviving partner to live on alone and the resulting psychological suffering, but these are, however, in themselves insufficient to justify euthanasia.

E.2 Question 2: What is the legal basis to obtain euthanasia if the applicant is not terminally ill?

It is worth remembering that the legislator never intended to include the concept 'terminal stage' in the Euthanasia Act. Admittedly, the Act does lay down additional conditions to cater for situations where the physician believes that death is unlikely to occur in the near future. In that case, he/she must not only consult a second physician, who must examine the serious and incurable nature of the medical condition, on the one hand, and must establish that the physical or mental suffering cannot be alleviated, on the other, but is also obliged to call in a third physician to review the medical file, examine the patient and give his/her opinion on the constant, unbearable and unalleviable nature of the suffering, and on the quality of the request, i.e. whether it was voluntary, well-considered and repeated. This third physician must either be a psychiatrist or a consultant specialised in the pathology in question and must be independent of the patient, the attending physician and the second physician. Furthermore, a period of one month must lapse between the written request for euthanasia and the act itself. In other words, the Act does not stipulate that the patient must be in a terminal stage.

E.3 Question 3: Is there a societal need to clarify the concept of constant and unbearable psychological suffering, resulting from a serious and incurable disorder caused by accident or illness, that cannot be alleviated?

During the discussion of this third question, **three points of view** came to the fore at Committee level. The members who hold the **first point of view** believe that it would be inopportune to amend the Act as regards psychological suffering. These members believe that the legislator chose to leave some leeway for interpretation in the Act by defining certain concepts with a certain amount of indeterminacy. This is the case for psychological suffering which, in these members' minds, does not need to be conceptually clarified, determined or measured. Psychological suffering caused by a physical or psychiatric disorder forms part of the patient's subjective experience and must be taken into consideration by the physician. After all, it is he who has the responsibility to diagnose a - a. o. psychiatric – disorder and to establish the incurability of the disorder in question, on the one hand, and the link between the patient's suffering and the incurable disorder, on the other hand.

The members who underwrite the **second point of view** believe that the Act is not sufficiently clear and that, because of its lack of clarity, it is applied in a manner that does not tally with its spirit (see D.6. Ethical debate). From this perspective, **legislative amendments** to better specify certain of the Act's essential concepts and change some of its provisions, a. o. to take better account of the specificity of psychiatric disorders, are sought. This point of view does not dispute that euthanasia on grounds of psychological suffering in certain specific and exceptional situations can be acceptable however.

The advocates of these two points of view are at one on some points, such as the training of physicians and public education, the need for more research into the medical end-of-life-related decisions, the rejection of the medicalisation of various forms of social suffering, and the need to provide the Federal Control and Evaluation Commission on Euthanasia (FCECE) with adequate resources.

Finally, the members who adopt the **third point of view** are of the opinion that the Euthanasia Act should be thoroughly reviewed specifically to exclude the option of euthanasia purely on the grounds of psychological suffering caused by a psychiatric disorder without irreversible tissue injury.

E.3.1. Points of consensus

a. Physicians' training and public education

All the members recommend that medical training (basic and further training courses alike) should focus far more on an accurate knowledge of and critical reflection on the Euthanasia Act and its embedding in end-of-life practices, which is far broader than euthanasia alone, and also presupposes a knowledge of palliative care.[64] The medical training programmes should also put a greater emphasis on the role of physicians (both individually and in team) and on

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[64] -See http://leif.be/professionele-info/professionele-leidraad/: the End-of-Life Information Forum (LEIF) Guideline contains recommendations on how to complete the registration documents and on how to compile the report of the second and, possibly, the third (LEIF) physician.
-For the French-speaking forum "forum EOL" see http://www.admd.be/medecins.html.

their professional responsibility to critically reflect on the (un)acceptability of certain specific requests for euthanasia. Not only the clinical-technical but also the legal and ethical aspects should be dealt with in these lectures and training courses which should be hosted by experts in the field.

For one, reflection within the medical associations specialised in psychiatric disorders should be encouraged so as to fine-tune the diagnoses and protocols designed to establish whether a condition is incurable. The scientific psychiatric associations in our country – the *Vlaamse Vereniging voor Psychiatrie*, the *Société Royale de Médecine Mentale de Belgique* (SRMMB) and the *Belgian College of Neuropsychopharmacology and Biological Psychiatry* (BCNBP) – are best placed to draw up the relevant recommendations. Reflection within the various general practitioner associations should also be encouraged so as to improve GPs' knowledge of the diagnosis of psychiatric disorders, the possible treatments and the definition of incurability.

During medical training, physicians should be trained in the reflection and communication skills that are required to deal with requests for euthanasia with the necessary empathy, knowledge and self-confidence. In this respect, the general public should be far better educated and informed, this to avoid the current common misconception that the Act of 2002 *entitles* everyone to euthanasia while it only provides for the right to ask for euthanasia.

b. The need for more research into end-of-life-related decisions

All the members are in favour of an evaluation of the Act and of organising an inquiry of the medical end-of-life decisions, continuous palliative sedation included. This inquiry in question should also look into the euthanasia requests that have been turned down: in what environment, for which conditions, by which doctors, for which patients? These studies should be conducted across the entire territory as most of the studies relate to Flanders only.

c. No medicalisation (of various forms) of psychosocial suffering

All the members of the Committee agree that the approval of euthanasia requests purely based on constant and unbearable suffering, without a medical basis, would in fact open the door to an extreme form of medicalisation in areas where this would be utterly undesirable. Even if, for many, the suffering will be caused by a combination of psychosocial and medical problems, it should be the *medical* problems that are the cause of the constant and unbearable suffering, as stipulated in the Act of 2002 which decriminalises euthanasia.

We cannot expect the medical world to come up with or propose solutions for problems that are not of a medical nature. Suffering such as this is often caused by social indifference, which leads to isolation and alienation, and, in turn, culminates in legitimate feelings of loneliness, abandonment and uselessness. These widespread social problems urgently require a social, economic and political response, *not* a medical one and even less so one in the form of euthanasia.

As tiredness of life without medical basis does not meet the criteria of art. 3(1) of the Act, it cannot form an acceptable legal basis for euthanasia.

d. Incurability of the condition and unbearability of the suffering

Within the Advisory Committee on Bioethics there is a **consensus:** (1) that only suffering that meets the requirement that it **results from** a serious and incurable disorder caused by accident or illness can constitute a legal ground for euthanasia; (2) that it is the physician's responsibility to decide whether a serious disorder caused by accident or illness is *incurable*; and (3) that, conversely, the decision as to whether the physical or psychological suffering is *constant* and *unbearable* is the patient's to make. To establish whether a patient finds himself in a medically hopeless situation, the Act also refers to the condition that the 'suffering cannot be alleviated'. The members' positions on both the interpretation of the criterion 'unalleviable nature' of the suffering and on who decides whether the suffering can be alleviated or not vary.

E.3.2. Issues on which there is no consensus

a. As to the unalleviable nature of the suffering

Some members believe that the responsibility to decide whether or not a condition is incurable and whether or not the suffering can be alleviated rests with the medical profession and not with the patient. According to these members, patient autonomy cannot be the only ethical value that takes precedence in the assessment of requests for euthanasia. However, they do emphasise that only the patient can judge whether his/her suffering is constant and *unbearable* or not, but believe that it is essential that doctors take their clinical and ethical responsibility with regard to the other criteria of art. 3 (1) of the Act (i.e. the incurability of the condition and the impossibility to alleviate the patient's suffering), instead of leaving the evaluation of these criteria to the patient. As regards the assessment of the incurability of the condition, these members recommend that the evaluation should in essence be performed on the basis of treatment algorithms that are based on convincing scientific criteria, according to the state of the art, and which have been defined for various conditions. These treatment algorithms must be fine-tuned on a regular basis, in line with the latest findings.

Other members believe that patient autonomy is a crucial value and that there is nothing unethical about acceding to a request for euthanasia from a patient who, after having considered and often already tried all the proposed medical treatments, psychiatric treatments included, is of the opinion that he/she no longer wants to put up with the suffering he/she considers unbearable and unalleviable. According to these members, this is not a question of a physician delegating his/her responsibility to the patient, but about that physician embracing his/her responsibility and, in the context of the individual doctor-patient relationship and with the full extent of his/her competences, trying to contribute to this essential dialogue and reflection, rather than imposing his/her own views on what the concept of 'good life' entails. These members are most definitely in favour of looking for objectification criteria, notably by fine-tuning the treatment algorithms. They would be less so inclined if a procedure such as this would entail that a patient would have to justify his/her request for euthanasia time and again. This would undermine the law and lead to "tribunalisation", an option the legislator rejected. According to these members, physicians can take other precautions, alongside those the Act imposes. These do not need to be incorporated into the Act but could result from reflection within the relevant medical-scientific associations, without forgetting the patient in all of this. These members are of the opinion that the foregoing does not in any way suggest that the assessment of the unalleviable nature of the suffering is left to the patient. It goes without saying that only physicians have the relevant knowledge to medically alleviate suffering. However, these members do emphasise the importance of dialogue between doctor and patient. Suffering is by definition subjective and the unbearability of that suffering is closely linked to its constant nature, which is what causes the patient to perceive the suffering as hopeless and unalleviable. The patient's perception as to the alleviable or unalleviable nature of the suffering is shaped by the dialogue with his/her physician, in the course of which the latter will discuss the possible solutions with the patient.

Other members again believe that the legislation wrongly allows for euthanasia in cases of purely psychological suffering, because there is no consensus as to the possibility to establish that the psychological suffering caused by a psychiatric disorder without irreversible tissue injury is incurable or about the requirement that all therapeutic options have been exhausted.

These members argue that clinical practice has shown that a cure or sudden change in mood or general well-being can occur out of the blue, even against the patient's and the care providers' expectations, and many years later at times. Changes such as these can be triggered by a new therapeutic relationship or changing conditions in the patient's living environment. It is on that account that a sizeable group of psychiatrists and clinical psychologists are adamant that the concept "all avenues exhausted" is not objectifiable. For these psychiatrists and clinical psychologists, a decision on euthanasia emanates from a subjective assessment of the care context by both the care providers and patients.

b. As to the refusal of a treatment proposal

Patients are always free to refuse a treatment proposed to them. However, **some members** believe that if a patient turns down a reasonable, state-of-the-art treatment proposal, the legal requirement of medical hopelessness is no longer fulfilled, with the result that euthanasia is not an option. These members recommend that the scientific psychiatric associations in our country issue guidelines in that sense as a matter of urgency. Pending these, the Directive the Netherlands Psychiatric Association (NVvP) issued (in particular section 3, 5.1.1.) can serve as a useful guideline[65].

Other members point out that a therapeutic proposal and/or medical solution to alleviate the suffering does not give physicians the authority to decide whether or not the suffering is unbearable. In the end, that is the patient's decision to make but always in the context of continuous and open dialogue with his/her doctor. Building on this point of view, these members stress the importance of dialogue. To the extent that the suffering is closely linked to the underlying condition and the recommended treatments for that condition, these members believe that the issue of suffering can never be completely disassociated from the therapeutic decision, whether by the physician or the patient. Vice versa, when decisions are taken about treatments that are based on scientific evidence, the suffering they cause will, one way or the other, always be taken into consideration. Physicians take their decisions in consultation with others or after careful personal consideration and will always try to strike a balance between the hoped-for benefits of the treatments and the suffering they cause. It is about this latter aspect that the patient does have a say. More often than not, patients are given a say in the therapeutic decisions that affect them because they want to prevent current and/or future suffering, for instance because they are no stranger to suffering. This is also the reason why patients are allowed to refuse a treatment, in many cases another one in a long list of many. This is a refusal physicians can understand perfectly well and does not *a priori* lead to the presumption that it stems from some kind of irrational reflex on the part of the patient. In other words, these members are at one about the fact that it is the physician who must decide whether an illness is incurable or not. On the other hand, they find it extremely important that dialogue is pursued whenever a patient asks for euthanasia. During that dialogue, maximum empathy with the patient's suffering is essential. These members insist that, according to the Netherlands Psychiatric Association, a patient's refusal to sign up for an umpteenth treatment - where there is nothing to indicate that this refusal is not completely objective - does not detract from the patient's right to ask for euthanasia. The patients in question have proven to be "psychopharmacologically resistant" and have received psychotherapeutic treatment *on more than one occasion* in the past. Hence, what is relevant in cases like these is not the "objectivity of the treatment" but the accumulated extent of the

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[65] NVvP Directive Requests for assisted suicide from patients suffering from a psychiatric disorder, 2009, see https://www.nvvp.net/website/onderwerpen/detail/euthanasie (under Documents).

suffering a physician, as a human being, will be able to understand and which the physician will prioritise over the armoury of therapeutic treatments, an armoury which some believe to be infinite, especially in the field of psychiatry. According to these members, this kind of stance by a doctor should not simply be qualified as a delegation of that physician's responsibilities but as proof of that physician's humility in aid of his patient's human dignity. To them, this clear willingness to listen forms an integral part of a doctor's dialogue with his patient and is even the main reason for that dialogue.

c. As to age-related complaints, polypathology and tiredness of life

Within the Committee there is no discussion about the fact that the Euthanasia Act requires a medical basis - even if the suffering is perceived to be unbearable - before euthanasia can be an option and that old age is not a medical condition. However, the question that arises is how "medical basis" is defined. All the members agree that some forms of polypathology – i.e. the presence of several ailments - can be a medical basis to take a request for euthanasia into consideration provided that the unbearable *and* medically hopeless *and* unalleviable nature of the patient's suffering *is caused* by the polypathology in question. Within this consensus, opinions at Committee level vary.

Some members are receptive to the idea that a polypathology where each individual complaint does not provide a sound medical basis to qualify as a medically hopeless situation and a source of unbearable suffering but that the combination of ailments (e.g. poor balance, arthritis, osteoporosis, diabetes 2, severely impaired vision or hearing…) could meet the 'severe and incurable condition' criterion a request for euthanasia must meet, once the complaints in question are of a certain intensity and frequency.

To **other members** the *mere presence* of medical problems (which, from a certain age, tends to be the rule rather than the exception) does not suffice to justify a request for euthanasia since it does not satify the statutory requirement that the suffering must also be *the consequence* (*causal link*) of one or more conditions caused by accident or illness that are hopeless and incurable and not triggered by other non-medical factors, e.g. loneliness and/or financial pressure. These members comment that it is clear from the preparatory debates for the Euthanasia Act that the legislator did not deliberately resort to vague terms but, to the contrary, chose to word the Act in such a way that it is clear who qualifies for euthanasia and who does not. They take the view that the presence of multiple age-related complaints cannot constitute grounds for euthanasia.

Although tiredness of life without medical indication does not meet the legal requirements for obtaining euthanasia, patients can, in their euthanasia request, express tiredness of life as a complaint in combination with polypathology. In those circumstances, it must then be clarified what lies behind that complaint of tiredness of life. In the case of euthanasia requests with tiredness of life as motivation, a multidisciplinary assessment must therefore take place.

d. As to the *a priori* versus *a posteriori* evaluation of euthanasia requests

Some members state that the procedure to assess euthanasia declarations as set out in the Act is not suitable for the evaluation of requests for euthanasia formulated by patients on grounds of unbearable psychological suffering who are not terminally ill, e.g. because they are suffering either from a psychiatric disorder, either from a polypathology, whether or not combined with tiredness of life. Given the complexity, the unpredictability of the course of psychiatric disorders, the multifactoriality in polypathology/tiredness of life, the non/less urgent nature of a request for euthanasia and the irreversibility of euthanasia, they argue that in these cases an *a priori* assessment is indicated, with all the parties concerned, in first instance the patient himself, his trusted/attending care providers in a multidisciplinary team (under the final responsibility of a physician) and, where possible and subject to the patient's consent, also with the patient's nearest and dearest. This could be organised in the form of an *ad hoc* consultation process by a (to be established) decentralised review committee by Dutch exemple made up of both the aforesaid parties and independent experts. The idea is to ensure beforehand that the statutory criteria for euthanasia have indeed been fulfilled and that this assessment takes place in collegial consultation and does not limit itself to collecting opinions. Aside from formulating an approval or rejection, these decentralised review committees could also be tasked with formulating care-related suggestions. This *a priori* assessment would be complementary to the already existing evaluation and control *a posteriori*.

Other members vehemently oppose this proposal and refer to the spirit in which the Euthanasia Act of 2002 came about, where the legislator deliberately opted for an *a posteriori* instead of an *a priori* procedure, taking the view that the latter option would imply a "tribunalisation" of euthanasia requests. The legislator quite specifically rejected the *a priori* procedure formula. These members fail to see why, in cases of psychological suffering, whether based on a psychiatric disorder or not, this fundamental principle ought to change. Since there are a whole host of criteria to keep the assessment of special situations, such as those involving a psychiatric disorder, on the right track, there is no logical reason to review this fundamental legal provision.

e. As to the statutory waiting period between the request for euthanasia being made and granted in cases where death is unlikely to occur in the near future

In the seventh Federal Control and Evaluation Commission on Euthanasia report (2014-2015), a distinction is made between the statutory waiting period and the reflection period. The statutory waiting period is one month as of the day the request for euthanasia is put in writing and the day it is executed. The term “reflection period” refers to “the decision-making process that precedes the written confirmation of the request for euthanasia” (p 54, our translation).

Some members believe that the statutory waiting period of minimum one month should not be changed because, in practice, people would have been contemplating the idea of euthanasia for quite some time, while **other members** believe that the statutory waiting period does not provide a cast-iron guarantee.

The latter members recommend that, in the case of psychiatric disorders, the statutory minimum period between the written request for euthanasia and the request being granted should not be less than one year (currently one month pursuant to art. 3 §3,2° of the Euthanasia Act).

According to these members one month is too short for the complex assessment of, inter alia, the patient’s competency, the layers of meaning of the request for euthanasia, the unbearable psychological suffering and the medical hopelessness. Assessing the medical hopelessness takes expertise and time: following the proposed due care criteria and exploring all possible, reasonable interventions and chances of recovery and reducing the suffering (see the aforementioned state-of-the-art treatment algorithms), takes a minimum of one year. These members do not doubt that, in many cases, a lengthy process will have been gone through before the request for euthanasia is made. The formal formulation of a request for euthanasia creates a new situation however, one that triggers another process, with a different dynamic and finality. That process should be accorded the necessary time and chances to facilitate recovery while it is still possible.

Other members point out that the term of one month is a *minimum* term. It is up to the parties concerned - the patient, physicians, psychiatrists or the multidisciplinary team – to adapt, depending on the case. Even though psychiatric disorders, for one, display common characteristics, such as the difficulty to establish their incurability, it has to be said that no two disorders or no two patients are the same. Imposing a term of one year, during which the patient has to start the entire process, i.e. talking to physicians, let alone hospitalisation, from scratch again could drive a patient, who has been through numerous treatments already and did attempt suicide before, to despair, and, in turn, to another suicide attempt.

Other members, for their part, believe that a request for euthanasia on grounds of purely psychological suffering by definition excludes death in the near future, with the result that any attempt to, by law, set a 'reasonable' period of time between the request for and the granting of euthanasia is impossible. If the Act was to ban euthanasia on grounds of psychological suffering alone, the issue wouldn't arise in the first place. For that reason, these members argue that euthanasia for reasons of psychological suffering caused by a psychiatric disorder without irreversible tissue injury should be removed from the Euthanasia Act.
According to those who embrace this view, the incorporation of extra due care criteria into the euthanasia pathway (longer waiting period, additional opinion of an ethics committee, unanimity between physicians, asking the patient to avail of all the therapies first) does not offer this group of extremely vulnerable patients the protection they need when they are genuinely gripped by a wish to die. According to these members, the Act, as it currently stands, allows a patient in this type of situation to autonomously look for a psychiatrist who is prepared to ignore these legally unenforceable due care criteria in the name of the right to autonomy.

f. As to the required expertise of the executing and consulted physicians

Some members state that the procedure to assess requests for euthanasia must be clearly described[66] to ensure that they are met with careful consideration, the relevant diagnostic and (psycho)therapeutic expertise (i.e. expertise in the actual condition and all the relevant guidelines and state-of-the-art treatment modalities have been pursued), expertise in palliative care, end of life and euthanasia, expertise in assessing the patient's competence to express his/her will and psychotherapeutic expertise to explore the layers of meaning of the request for euthanasia. In these members' minds that implies that, in cases where a patient suffering from a psychiatric disorder asks for euthanasia, only a psychiatrist is in a position to decide that the patient has received all the state-of-the-art treatments and genuinely finds himself in a medically hopeless situation, in other words, that his/her condition is beyond cure and that there is no way of alleviating his/her suffering. For these members, this entails that, in the case of requests for euthanasia from patients suffering from a psychiatric disorder, *two* of the *three* physicians should be psychiatrists.

In the case of requests for euthanasia on grounds of polypathology, combined with tiredness of life or not, these members believe that the third physician should be a specialist in the condition, e.g. a geriatrician, psychiatrist, a geriatric psychiatrist, ... and not a general practitioner.

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[66] One example of a clear procedure has been described in Behaegel, J.; Vercoutere, S.; Matthys, D. (2015), "Euthanasie bij psychiatrische patiënten [Euthanasia in psychiatric patients]", *Tijdschr. voor Geneeskunde*, 71, no. 17, pp. 1086-1089, doi: 10.2143/TVG.71.17.2001931.

Other members believe that the Act does provide the necessary guarantees for sound euthanasia practices. The physician who receives the request for euthanasia will ask a second physician for an opinion. That opinion must meet the conditions set out under the Act, i.e. a review of the medical file, an examination of the patient and the conclusion that the physical or psychological suffering is constant, unbearable and cannot be alleviated. The physician consulted will compile a report of his findings, meaning a decision whether or not the statutory requirements have been fulfilled. The physician consulted must have the relevant expertise to assess the condition in question. It goes without saying that the requesting physician will ask a colleague whom he/she knows not to have any moral issues with the actual practice of euthanasia for an opinion. After all, the opposite would be unworkable in practice. The physician consulted will obviously have to give an opinion on the individual case, with due regard for the statutory due care criteria and any additional measures this physician might like to see implemented. Examples that spring to mind are the obligation to inform the patient's nearest and dearest, which is not a statutory requirement but one that many doctors who pursue sound practices will adhere to. Where a patient is not expected to die in the near future, a third physician must be consulted, who must either be a psychiatrist or a specialist in the condition. The qualification 'specialist (consultant)' means that this third physician practices a recognised specialty and cannot be replaced by a doctor with any post-graduate certificate.

g. As to the status of the opinions of the physicians consulted

Some members argue that the current statutory procedure on the opinions of the physicians consulted gives the attending physician too much leeway. In the context of a euthanasia procedure for an adult or emancipated minor, the attending physician is in fact free to ignore the opinion of the second (and, as the case may be, third) physician.

These members do agree however that a negative opinion from a second or third physician does not preclude that another physician may be consulted who may come to a different conclusion. If not, you could end up with a situation where the refusal by the first physician consulted would bring the procedure to a complete, possibly unjustified, standstill. Given the need to make all the physicians involved in requests for euthanasia aware of their responsibilities, these members recommend that each physician consulted would personally submit his or her positive or negative opinion to[67] the Federal Control and Evaluation Commission on Euthanasia (in contrast to the current legal procedure where the executing/reporting physician is left to summarise the opinions of the physicians consulted).

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[67] As provided in the Dutch euthanasia procedure where the physicians consulted report to the regional review committees themselves, see the Dutch record sheet in annex 1. See also the link: http://www.euthanasiecommissie.nl/toetsingsprocedure/uitspraken/formulieren/meldingsformulieren/verslag-melding-behandelend-arts/verslag-melding-behandelend-arts/modelverslag-behandelend-arts.

Other members deem the statement that the opinions of the physicians consulted would not be binding to be a controversial one: they wonder how a physician would be able to ignore an opinion refuting the serious and incurable nature of a given medical condition, of an opinion that does not confirm the reality of physical or psychological suffering that cannot be alleviated or one that states that there is no question of a clear, voluntary and repeated request for euthanasia, while these are the essential conditions laid down in the Act. These members believe that there is no need for a legislative change because they consider that they are deemed binding in practice, or, in any event, considered important steps in the decision-making process, as they enlighten the attending physician and fuel dialogue, while leaving the responsibility for the final decision to the physician and the patient.

In this respect, the first aforementioned members ('Some members') wish to point out that empiric studies have shown that it is not all that unusual for opinions to be ignored or not sought in the first place[68] and for euthanasia to be proceeded to anyhow.

h. As to the role of the Federal Control and Evaluation Commission on Euthanasia (FCECE) set up to monitor the implementation of the Euthanasia Act

Some members state that the Federal Control and Evaluation Commission on Euthanasia can play an important role in enhancing clarity via transparency. They recommend that, in addition to its biennial reports, the FCECE should publish a selection of anonymised (in terms of the patient and the physician) and concise summaries of reported cases of euthanasia on its website so that every physician, citizen, policy maker, etc. could get a picture of how the Commission rules in specific cases. In the Netherlands, the Regional Euthanasia Review Committees always include a number of anonymised cases in their annual reports to create transparency on how the Committee rules in certain cases. These members recommend that

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[68] **These members** refer to the following two studies on the basis of which they consider that their specific recommendations on the status of the opinions of the physicians consulted are justified: these studies show that recklessness on the part of some physicians is not beyond the bounds of possibility.

(a) Van Wesemael, Y., Cohen, J., Bilsen, J., Smets, T., Onwuteaka-Philipsen, B., Deliens, L. (2011) "Process and outcomes of euthanasia requests under the Belgian act on euthanasia: a nationwide survey". *Journal of Pain and Symptom Management*, 42(5): 721-733. The table on p 727 363 of the publication by the End-of-Life-Care Study Group describes cases of euthanasia:
- in four cases euthanasia was performed in spite of a negative second opinion;
- in four cases euthanasia was performed pending the report of the second physician; and
- in 20 cases euthanasia was performed without a second physician having been consulted.

It concerns a survey study among physicians and it is not clear whether these cases were also reported to the Federal Control and Evaluation Commission on Euthanasia (the research of this study group shows that cases that are not reported usually do not meet several of the statutory requirements).
According to **other members**, these cases may not be euthanasia in the sense of the law, and therefore should not be reported to the FCECE. In any case, the FCECE has so far received no reports of cases where the opinion of the physician consulted was missing.

(b) Supplementary Appendix to Chambaere K, Vander Stichele R, Mortier F, Cohen J, Deliens L. "Recent trends in euthanasia and other end-of-life practices in Belgium". N Engl J Med 2015;372:1179-81. DOI:10.1056/NEJMc1414527, table S1, p 4.
(http://www.nejm.org/doi/suppl/10.1056/NEJMc1414527/suppl_file/nejmc1414527_appendix.pdf).
In this particular frequency study it was established that, during 2013, over a period of six months, no second physician was consulted in 7.4 % of the 349 cases (table S1, p 3).

the FCECE would produce a summary of one tenth of the number of cases reported each year. All the categories of conditions dealt with in the annual report should be proportionally represented in this selection and especially the more complex cases should be discussed in each category.

The members concerned also recommend that the anonymity of physicians reporting[69] euthanasia cases to the FCECE should be lifted at FCECE level, on the understanding obviously that the members of the FCECE do remain bound by their duty of discretion. This proposal tallies with the Dutch procedure where all the members of the Regional Euthanasia Review Committees are given the names of the executing and consulted physicians.[70]

Other members (some of whom with experience of the work of the FCECE) believe that this proposal would be unworkable in Belgium. The Dutch Regional Euthanasia Review Committees can take a case-specific approach on the basis of highly detailed and non-anonymous statements from physicians, which more specifically includes the patient’s prior history (anamnesis). The FCECE either accepts or rejects a euthanasia declaration but does not issue a substantiated opinion. However, the seventh FCECE report 2014-2015 dedicates a specific section to psychiatric disorders and cases of polypathology.[71]

Other members believe that it is time to start producing non-anonymous, transparent, and well documented reports on or declarations of each euthanasia case to the FCECE, along the lines of the Regional Euthanasia Review Committees. Such an adjustment of the FCECE modus operandi and procedures will have to form part of a thorough review of the Euthanasia Act.

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[69] The registration document consists of two parts. Part I must be sealed by the physician, is confidential and is transmitted to the Commission by the physician. Part I cannot be consulted until such time as the Commission has taken its decision. Under no circumstances is the Commission allowed to use it as a basis for its evaluation task. Part I inter alia features the details of the patient, the attending physician and the physician(s) consulted. (See article 7 of the Euthanasia Act).

[70] See annex 1.

[71] To consult the seventh report of the FCECE, see: http://overlegorganen.gezondheid.belgie.be/nl/documenten/fcee-euthanasie-verslag-2016

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COURT DECISIONS

Hoge Raad (2002) HR:2002:AE8772 (Brongersma)

This opinion was prepared by the select commission 2014/1, consisting of:

Joint chairpersons	Joint reporters	Members	Member of the Bureau
Martin HIELE	Sigrid STERCKX	Dominique BRON	Paul COSYNS
Guy LEBEER	Jacqueline HERREMANS	Patrick CRAS	
		Wim DISTELMANS	
		Martine DUMONT	
		Evelyne LANGENAKEN	
		Willem LEMMENS	
		Julien LIBBRECHT	
		Dominique LOSSIGNOL	
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		Richard REGA	
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Member of the secretariat
Veerle Weltens

Experts interviewed
Nele VAN DEN NOORTGATE, prof. dr., Geriatrician UZ Gent
Herman NYS, prof., expert health law, KU LEUVEN

The working documents of the select commission 2014/1 – the question, personal contributions of the members, minutes of the meetings and documents consulted - are kept on file at the Committee's documentation Centre where they are available to be consulted and copied.

* * *

This opinion is available on www.health.belgium.be/bioeth.

Annex 1

The Netherlands: Model of a report by the attending physician produced on the basis of the due care criteria as referred to in article 2 of the Dutch “Termination of Life on Request and Assisted Suicide Act”. (original version in Dutch)

INLEIDING

Dit betreft een elektronische versie van het model voor een verslag van de behandelend arts in verband met een melding aan de gemeentelijke lijkschouwer van het overlijden als gevolg van de toepassing van de levensbeëindiging op verzoek of hulp bij zelfdoding. Het model is bij besluit 12 maart 2016 vastgesteld (Staatsblad 2016, 110) en van kracht per 1 juli 2016.

De KNMG heeft dit formulier bewerkt, waardoor het op de computer is in te vullen. Met dit elektronische formulier kunt u verslag doen. De KNMG is op geen enkele wijze verantwoordelijk voor de inhoud en/of het gebruik van dit formulier. Zie ook www.knmg.nl.

TECHNISCHE INSTRUCTIE

- Het formulier is gemaakt in Microsoft Word.
- Vul uw eigen persoonsgegevens (éénmalig) in en sla deze op via Bestand *(File)*, Opslaan als *(Save as)*, met een logische naam op uw vaste schijf van de computer, bijvoorbeeld Modelverslag Melding Behandelaar.doc. Dit bestand kunt u bij eventuele volgende meldingen gebruiken.
- Het zojuist gemaakte bestand Modelverslag Melding Behandelaar.doc nogmaals opslaan via Bestand, Opslaan, met een logische naam bijv. Modelverslag Melding Behandelaar Datum Naam.doc. Dit is dan het actieve werkbestand ten behoeve van de betreffende melding.
- De tekst van de vragen kunt u niet wijzigen.
- De ruimte voor de beantwoording van de vragen zijn de gearceerde velden.
- Met de Tab-toets gaat u van vraag naar vraag.
- Bij het beantwoorden van een vraag kunt u met Shift-Enter naar een volgende regel.
- De arceringen worden niet geprint.
- Een fraaie pagina-indeling wordt bereikt door aan de antwoordvelden enkele witregels (met Shift-Enter) toe te voegen. Dit hangt mede af van uw printerinstellingen.

Deze toelichtingspagina is niet beveiligd zodat u deze desgewenst kunt verwijderen.

HOE VOORKOM IK VRAGEN VAN DE REGIONALE TOETSINGSCOMMISSIE EUTHANASIE EN BESPOEDIG IK DE OORDEELSVORMING?

De Regionale toetsingscommissies euthanasie toetsen (RTEe) achteraf het handelen van de meldend arts aan de hand van de in de Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding aan de hand van de zorgvuldigheidseisen.

Om te zorgen dat de afhandeling zo snel als mogelijk verloopt is het zaak om:

- volledig verslag te doen, bij voorkeur op de pc;
- alle vragen te beantwoorden en een nadere motivering te geven;
- voor de consultatie een SCEN-arts te raadplegen en te controleren of het verslag voldoende informatie bevat;
- de levensbeëindiging op verzoek precies uit te voeren volgens de KNMG/KNMP Richtlijn Uitvoering euthanasie en hulp bij zelfdoding, augustus 2012. Vul ook de gebruikte middelen, doseringen, wijze van toediening(sweg) en tijdsverloop in.
- de melding van een hand- en dagtekening te voorzien.

Mocht de Rte toch vragen hebben, beantwoord deze dan zo snel en compleet mogelijk.

MODEL voor een VERSLAG van de BEHANDELEND ARTS

In verband met een melding aan de gemeentelijke lijkschouwer van het overlijden als gevolg van de toepassing van de levensbeëindiging op verzoek of hulp bij zelfdoding.

Bij melding aan de gemeentelijke lijkschouwer van een niet-natuurlijke dood als gevolg van levensbeëindiging op verzoek of hulp bij zelfdoding verstrekt de behandelend arts aan de gemeentelijke lijkschouwer een beredeneerd verslag dat is opgesteld volgens onderstaand model. Met behandelend arts wordt bedoeld *de arts die de levensbeëindiging op verzoek (euthanasie) heeft uitgevoerd of hulp bij zelfdoding heeft verleend.*

Dit model is opgesteld aan de hand van de zorgvuldigheidseisen, bedoeld in artikel 2 van de Wet toetsing levensbeëindiging op verzoek of hulp bij zelfdoding.
Om de toetsingscommissie in staat te stellen zo goed mogelijk een oordeel te geven over de naleving van de zorgvuldigheidseisen, is het van belang dat u de *antwoorden op de gestelde vragen motiveert*. Daarbij kan nadere informatie zoals:

- een schriftelijke wilsverklaring;
- een specialistenbrief;
- een (gedeelte) van het patiëntjournaal;

een waardevolle bijdrage leveren. Indien de ruimte voor de beantwoording van een vraag tekort schiet, 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.

In dit model wordt alleen de term “levensbeëindiging op verzoek” gebruikt. Hiermee wordt zowel euthanasie als hulp bij zelfdoding bedoeld. Bij euthanasie dient de arts de dodelijke middelen aan de patiënt toe. Bij hulp bij zelfdoding ontvangt de patiënt van de arts de middelen die de patiënt zelf inneemt.

Met de term “patiënt” wordt in dit model zowel man als vrouw bedoeld.

GEGEVENS BEHANDELEND ARTS

Voorletters:

Tussenvoegsel:

Achternaam:

Geslacht: ☐ man ☐ vrouw

Instellingsnaam
Voorzover van toepassing

Werkadres:

Postcode:

Woonplaats:

Telefoonnummer:

E-mail:

Functie:
- ☐ huisarts
- ☐ medisch specialist → naam specialisme:
- ☐ specialist ouderengeneeskunde
- ☐ andere arts, namelijk:

GEGEVENS OVERLEDENE

Voorletters:

Tussenvoegsel:

Achternaam:

Geslacht: ☐ man ☐ vrouw

Datum van overlijden:

Geboortedatum:

In welke plaats overleed patiënt?

Waar heeft het overlijden plaatsgevonden?

- ☐ thuis
- ☐ verpleeghuis
- ☐ anders, namelijk:
- ☐ familie
- ☐ hospice
- ☐ verzorgingshuis
- ☐ ziekenhuis

UITZICHTLOOS EN ONDRAAGLIJK LIJDEN

1. Aan welke aandoening, die aanleiding was voor het verzoek tot levensbeëindiging leed de patiënt en sinds wanneer?
   Voeg, indien aanwezig, een of meer specialistenbrieven toe waarin de diagnose wordt gesteld.

2. Door wie en wanneer is de patiënt voorgelicht over (de huidige situatie, het beloop, de prognose van) het ziekteproces?

3. Welke therapeutische en palliatieve alternatieven zijn met patiënt besproken, inclusief de voor- en nadelen, en wat was de mening van de patiënt daarover?

4. Welke therapeutische maatregelen zijn ingezet en wat was daarvan het resultaat?
   Methoden, middelen, dosering.

5. Welke palliatieve maatregelen zijn ingezet en wat was daarvan het resultaat?
   Methoden, middelen, dosering.

6. Beschrijf – vanuit het perspectief van de patiënt – waaruit zijn lijden bestond en wat dat lijden voor deze patiënt ondraaglijk maakte?

7. Waarom bent u ervan overtuigd dat het lijden naar heersend medisch inzicht uitzichtloos is?

8. Wat maakte dat het ondraaglijke lijden van deze patiënt voor u invoelbaar was?
   Beschrijf bijvoorbeeld de klachten of aspecten van het lijden en de (niet alleen medische) zorg die de patiënt nodig had.

VRIJWILLIG EN WELOVERWOGEN VERZOEK

9. Wanneer is er voor het eerst *in algemene* zin door de patiënt (met u) over levensbeëindiging op verzoek gesproken?
   Als de patiënt *toen* een schriftelijke wilsverklaring heeft overhandigd, alstublieft de datum van de verklaring vermelden.

10. Beschrijf *wanneer* de patiënt voor het eerst aan u om *daadwerkelijke* uitvoering van levensbeëindiging heeft verzocht en wanneer de patiënt dit verzoek heeft herhaald?
    Als dit verzoek eerder aan anderen (bijvoorbeeld collega's) is geuit of als daar anderen (bijvoorbeeld verpleegkundigen of verzorgenden) bij waren, dit alstublieft vermelden.

11. Als er een (schriftelijke) wilsverklaring aanwezig is, voeg deze dan toe.
    Een schriftelijke wilsverklaring is geen wettelijk vereiste, maar kan aan arts en consulent soms meer duidelijkheid verschaffen met betrekking tot het verzoek om levensbeëindiging. Dat zelfde geldt voor video -of audiomateriaal dat is vervaardigd, bijvoorbeeld omdat een patiënt niet (meer) in staat is te schrijven. Indien gewenst kan ook dit materiaal worden bijgevoegd.

12. Waaruit hebt u afgeleid dat het verzoek van de patiënt *niet* is geuit onder druk of invloed van anderen?

13. Waaruit hebt u afgeleid dat de patiënt zich ten volle bewust was van de strekking van het verzoek en van zijn situatie?

CONSULTATIE

14. Welke arts heeft u geraadpleegd of geconsulteerd over het verzoek van de patiënt?
U moet volgens de wet ten minste één onafhankelijke arts hebben geraadpleegd die de patiënt heeft gezien en schriftelijk zijn oordeel aan u heeft geven over de zorgvuldigheidseisen. Voeg alstublieft het consultatieverslag toe.

Voorletters:

Tussenvoegsel:

Achternaam:

Geslacht: ☐ man ☐ vrouw

Instellingsnaam:
Voor zover van toepassing

Werkadres:

Postcode:

Woonplaats:

Telefoonnummer:

E-mail:

Functie:
☐ huisarts
☐ medisch specialist → naam specialisme:
☐ specialist ouderengeneeskunde
☐ andere arts, namelijk:
☐ tevens SCEN-arts

15. Wanneer heeft de geraadpleegde arts de patiënt bezocht? Datum:

16. Motiveer waarom u en de geraadpleegde arts onafhankelijk zijn ten opzichte van elkaar.

17. Had de geraadpleegde arts een behandelrelatie met patiënt?
☐ nee
☐ nee, maar patiënt is wel in de waarneming door de geraadpleegde arts gezien
☐ ja, ooit gehad maar dat is langer dan maanden geleden
☐ ja

18. Heeft u voor een *tweede* maal een onafhankelijke arts geraadpleegd over het verzoek van patiënt?

Indien een geraadpleegde onafhankelijke arts de patiënt heeft bezocht *geruime* tijd vóór het overlijden verdient het aanbeveling voor de tweede maal een onafhankelijke arts te raadplegen. Voeg alstublieft het 2^e consultatieverslag toe.

☐ nee → ga naar vraag 20
☐ ja → Was dit dezelfde arts als bij de eerste raadpleging?
  ☐ ja → ga naar vraag 19
  ☐ nee → Vul hieronder de gegevens in van deze *tweede* onafhankelijke arts (zie vraag 14, 16 en 17)

19. Wanneer heeft de tweede geraadpleegde arts de patiënt bezocht?
Datum:

UITVOERING VAN DE LEVENSBEËINDIGING OP VERZOEK

20. Door wie werd de levensbeëindiging op verzoek uitgevoerd of de hulp bij zelfdoding (door het aanreiken van de middelen) verleend?

→ Naam: ....

21. **Wijze van uitvoering**

☐ Hulp bij zelfdoding: de patiënt nam het euthanaticum zelf in of bracht het in via een enterale sonde → Ga naar vraag 22.a
☐ Levensbeëindiging op verzoek: de arts diende de euthanatica toe aan de patiënt → Ga naar vraag 22.b
☐ Een combinatie van hulp bij zelfdoding en levensbeëindiging op verzoek→ Ga naar vraag 22.c.

22.a **Hulp bij zelfdoding**

Haal door wat niet van toepassing is:
De patiënt nam het euthanaticum zelf in / bracht het euthanaticum zelf in via de enterale sonde.

Welke middelen werden gebruikt? ....
Wat was de dosering in grammen? ....
Hoeveel tijd verliep tussen het innemen of inbrengen van het euthanaticum en het overlijden? .... minuten.

22.b **Levensbeëindiging op verzoek**

Welk coma-inducerend middel werd gebruikt? ....
Wat was de dosering in mg? ....

Wat was de toedieningswijze?

☐ injectie (intraveneus)

☐ elastomeerpomp

☐ infuus

☐ anders, namelijk: ....

Op welke wijze heeft u vastgesteld dat er sprake was van een voldoende diep coma?

Welk spierrelaxans werd gebruikt? ....

Wat was de dosering in mg? ....

Wat was de toedieningswijze?

☐ bolusinjectie (intraveneus)

☐ anders, namelijk: ....

Tijdstip toediening coma-inductor . uur

Tijdstip toediening spierverslapper . uur

Tijdstip overlijden . uur

22.c **Een combinatie van hulp bij zelfdoding en levensbeëindiging op verzoek**

Haal door wat <u>niet</u> van toepassing is:
De patiënt nam het euthanaticum zelf in / bracht het euthanaticum zelf in via de enterale sonde.

Welke middelen werden gebruikt? ....

Wat was de dosering in grammen? ....

Na hoeveel tijd werd besloten dat het overlijden te lang uitbleef? minuten

Welk coma-inducerend middel werd vervolgens gebruikt? ....

Wat was de dosering in mg? ....

Wat was de toedieningswijze?

☐ injectie (intraveneus)

☐ elastomeerpomp

☐ infuus

☐ anders, namelijk: ....

Op welke wijze heeft u vastgesteld dat er sprake was van een voldoende diep coma?

....

....

....

Welk spierrelaxans werd gebruikt? ....

Wat was de dosering in mg? ....

Wat was de toedieningswijze?

☐ bolusinjectie (intraveneus)

☐ anders, namelijk: ....

Tijdstip toediening coma-inductor . uur

Tijdstip toediening spierverslapper . uur

Tijdstip overlijden . uur

23. Deden zich bij de uitvoering problemen voor? ....

Zo ja, beschrijf deze en beschrijf uw handelwijze.

....

....

....

....

....

OVERIGE OPMERKINGEN

24. Zijn er nog punten die u onder de aandacht van de regionale toetsingscommissie euthanasie wilt brengen en die u bij de beantwoording niet kwijt kon?

....

Datum: Handtekening: