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## EDITORIAL

### Euthanasia and palliative care: friends or foes?

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WHO states that palliative care intends neither to hasten or to postpone death<sup>i</sup>. This implies that palliative care is never compatible with life-terminating actions like euthanasia and assisted suicide.

In Europe euthanasia and/or assisted suicide can be practiced in The Netherlands, Belgium, Luxembourg and Switzerland. Countries like England, France and Germany forbid life-terminating actions strictly. Professional associations of physicians and nurses support their viewpoint, although there seems to be some room for discussion about assisted suicide in England. Recently the House of Lords has decided that a husband of a patient - Debbie Purdy - who wants to be assisted in committing suicide in Switzerland will not be prosecuted for helping his wife. It stated unanimously that the present law that prohibited assisted suicide interfered with her right to respect for her private life.<sup>ii</sup> The Lords said that it would be a breach of her human rights not to allow her to end her life with respect and dignity. To allow people with incurable diseases and in a hopeless situation to die with respect and dignity is exactly the situation in which Dutch and Belgian physicians are permitted to practice euthanasia and assisted suicide. These people must have expressed their will explicitly and an independent physician must have reviewed the case on forehand. In the past many foreign physicians and politicians have criticized the Dutch and Belgian way of dealing with life-terminating acts. They suggested that the physicians in these countries practise euthanasia due to the lack of knowledge of the principles of palliative care and said that good palliative care and application of the right drugs can exclude the need for euthanasia. Indeed, in The Netherlands euthanasia and assisted suicide is practiced in about five percent of the patients who ask for euthanasia in any stage of their terminal disease.<sup>iii</sup> However, isn't it exactly the respect for the dignity of the patient that forms the heart of palliative care? If that is true, what are the arguments to separate euthanasia from palliative care? I prefer to defend the opposite: euthanasia may only be justifiable if it is executed within the framework of palliative care.

McKeown has summarised the task of a doctor as 'to assist us to come safely into the world and comfortably out of it, and during life to protect the well and care for the sick and disabled'.<sup>iv</sup> WHO pleads for an integrated approach of palliative care, including care for the psychological and spiritual aspects. This form of integrated care is commonly given by a multidisciplinary team of doctors, nurses and others. It requires attitude, expertise, organization, availability of workers and means and also education.

Can appropriate palliative care prevent euthanasia and assisted suicide completely? It will be the case in a large number of cases. However, it is also possible that improved communication between patient and caregiver which is a requirement for good palliative care, will it make easier for the patient to express their will concerning end-of-life decisions.

The reality of dying trajectories demonstrate that it is not always possible to prevent suffering and that not all patients want to be unconsciousness during a number of days, like in applying palliative sedation.

If in palliative care the patient is really the centre of attention and physicians have no realistic solutions to relief serious refractory symptoms, than euthanasia and assisted suicide may be practiced within the framework of good palliative care. In that case one can consider the relation between both as that of friends and not foes.

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# ORIGINAL PAPERS

## Requests for medical assisted suicide: eleven cases

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### Abstract

Eleven clinical cases are presented of elderly patients in the terminal phase of their disease. The patients were requesting physician's aid in ending their life (euthanasia). All patients were at the end of a complex and long suffering disease process, which was harder and harder to endure.

Euthanasia requests were done under the following terms: 5 patients were requesting physician's active intervention (active, voluntary euthanasia), some (6) were asking to stop the treatment, some (5) of them wanted to stop eating and drinking also, and others (1) were requesting a lethal cocktail provided by the physician to commit suicide (medical assisted suicide).

The doctor – patient relationship is at stake under these uncommon circumstances in all its aspects (helping, information, trust, support, ethics). The focus in these cases has been on the interaction and on moral and psychological difficulties for rejecting such requests, not concordant with physician's ethics and palliative medicine doctrine.

Key words: *terminal patients, euthanasia requests, physicians' attitude*

(Full text in Romanian)

# CLINICAL LESSONS

## The particularities of the attitude in front of death of a young cancer patient family. The stress of professional caregivers

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### Abstract

Medicine promotes the idea that death is a failure of the professional caregivers. This idea has a major influence on the attitude of professional care givers, but also of family of a patient with a terminal disease. In this article the emotional and psychological distress of the professional caregivers is presented in the case of a relatively young cancer patient.

The patient, a 28 years man, a student originally coming from a rural area, was admitted at the Oncology- Palliative Ward of "St. Luke" Hospital in Bucharest. He was transferred from the Oncology Institute, diagnosed with neuro-endocrine tumour of the steroidal sinus, no Hodgkin lymphoma and with symptoms as paresthesias, headache and fatigue. The patient had accepted his diagnosis and prognosis from the beginning. Communication between patient and professionals was open and good.

The particularity of this case were the difficulties in communication between the patient and his family( his mother, brother, wife and mother in law), and between the palliative care team and the patients' family.

The patient was, because of these communication problems, transferred to another hospital after three weeks. The team of professional caregivers in St Luke analysed the impact of this case on the team members after transferral of the patient.

Accordingly to the team, not only the patient and his family were affected by a lot of stress because of the communication problems, but also the professional caregivers. The communication with the family and their attitude to the caregivers was one of the major stressors, but also the fact that the family had 'idealistic' and not realistic expectations. Critical situations appear when the patient wishes are not the same with the family wishes. The bad communication was considered the main stressor, additionally to occupational stress, related to the terminal disease and end of life situation.

Other stressors were: the lack of communication inside the team and with the others of the system, lack of support from colleagues from other specialities, inadequate resources and staffing.

The coping mechanisms used were: personal philosophy, development of the communication abilities, support from the family, friends and colleagues..

Key words: *difficulties in communication, stress, palliative care team*

(Full text in Romanian)

# MANAGEMENT

## Legislation of euthanasia: the Dutch case

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### Abstract

After a discussion over more than two decades the Dutch Parliament approved a law, allowing euthanasia and physician assisted suicide under strict conditions. Euthanasia is still a part of the Criminal Code, but doctors, executing euthanasia, will not be prosecuted when they fulfil due care requirements. These requirements include free will of the patients, hopeless and unbearable suffering, full information and a written second opinion of an independent doctor.

Each euthanasia case has to be reported. A special committee reviews each case. If requirements are not met the case will be brought to the public prosecutor. The 'euthanasia law' is seven years in practice in the Netherlands. The number of euthanatized patients is increasing. In the same period the Netherlands developed an extensive palliative care service.

Dutch citizens as well as physicians support the legislation and it works well in practice. It is discussed that euthanasia and palliative care have both their merits and expertise. When palliative care services are available and euthanasia is legalised human beings, suffering from a terminal disease, have their own choice how to live and die.

Key words: *euthanasia, physician assisted suicide, palliative care, legislation*

### Introduction

In 2001 the Dutch Parliament approved the Termination of Life on Request and Assisted Suicide Act (1). It legalized euthanasia and physician assisted suicide in very specific cases, under very specific circumstances. It became effective as law in 2002. Euthanasia is still a criminal offence but the law codified a twenty-year old convention of not prosecuting doctors who have committed euthanasia in specific circumstances. The Criminal Code of the Netherlands contains a variety of provisions prohibiting the intentional taking of human life.

By this legislation, the Dutch government tried to regulate a careful procedure, which made euthanasia and physician-assisted suicide possible (2). In doing so, the government was reacting to the need, which was felt in practice, i.e. the possibility to assist hopeless, unbearable suffering of patients by a doctor, mostly the family doctor. And euthanasia was practiced, which created much insecurity and misunderstanding in the Dutch society.

When the discussion on euthanasia started in the Netherlands palliative care was not well developed. Shortly before the law on euthanasia became effective, the Dutch government started a stimulation programme for palliative care. Since then, palliative care services have shown a strong increase in the Netherlands.

This article describes the content of the law and presents some data on euthanasia and physician assisted suicide after the law came into practice. In the discussion the often supposed relationship between palliative care and euthanasia will be discussed.

## Legal frame work

The Dutch euthanasia act states that euthanasia and physician assisted suicide are not punishable if the attending physician acts in accordance with criteria of due care (1). These criteria concern the patient's request, the patient's suffering (unbearable and hopeless), the information provided to the patient, the presence of reasonable alternatives, consultation of another physician and the applied method of ending life (2,3,4). To demonstrate their compliance, the law requires physicians to report euthanasia to a review committee (2). The doctor must also report the cause of death to the municipal coroner in accordance with the relevant provisions of the Burial and Cremation Act. It should be noted that other forms of termination of life or assistance with suicide are part of the Criminal Law. However, exceptions are decisions considered as normal medical practice:

- stopping or not starting a treatment at the patient's request,
- stopping or not starting a medically useless (futile) treatment,
- speeding up death as a side-effect of treatment necessary for alleviating serious suffering

The law allows medical review committee (see later) to suspend prosecution of doctors who performed euthanasia when each of the following conditions is fulfilled:

- the patient's suffering is unbearable with no prospect of improvement
- the patient's request for euthanasia must be voluntary and persist over time (the request cannot be granted when under the influence of others, psychological illness or drugs)
- the patient must be fully aware of his/her condition, prospects and options
- there must be consultation with at least one other independent doctor who needs to confirm the conditions mentioned above
- the death must be carried out in a medically appropriate fashion by the doctor or patient, in which case the doctor must be present
- the patient is at least 12 years old (patients between 12 and 16 years of age require the consent of their parents)

The legislation also offers an explicit recognition of the validity of a written declaration of will of the patient regarding euthanasia (a "euthanasia directive"). Such declarations can be used when a patient is in a coma or otherwise unable to state if they wish to be euthanized.

## Due care requirements

The due care criteria which must be met in order to obtain exemption from criminal liability require that the attending physician:

- ensures that the patient has made a voluntary and well considered request
- ensures that the patient's suffering is unbearable, and that there is no prospect of improvement
- has informed the patient about his or her situation and prospects
- has come to the conclusion, together with the patient, that there is no reasonable alternative in the light of the patient's situation
- has consulted at least one other physician, who must have seen the patient and given a written opinion on the due care criteria referred to above, and
- has terminated the patient's life or provided assistance with suicide with due medical care and attention.

## Regional review committees

A regional review committee assesses whether a case of termination of life on request or assisted suicide complies with the due care criteria. Depending on its findings, the case will either be closed or, if the conditions are not met brought to the attention of the Public Prosecutor.



Each regional review committee, of which there are five, is composed of an uneven number of members. It must consist of a legal expert, a doctor and an expert in the field of ethics or philosophy.

The committees assess whether a case of termination of life on request or assisted suicide complies with the due care criteria. The committee is required to notify the physician of its findings, giving reasons.

Where a committee is of the opinion that the physician did not act in accordance with the due care criteria, the case must be brought to the attention of the public prosecutor which then may launch a criminal investigation.

Regional committees have the capacity to personally discuss with the physician the assessment given and through annual reports contribute to public debate and awareness of termination of life on request and assisted suicide and the supervision exercised.

### Some data of 2008

In the Netherlands, in 2008 the 2331 cases were reported, an increase of 10% as compared to 2007 (5). These cases are about 1.3% of all deaths. In 2003, the year after the law came to order, in total 1778 cases were reported, of which 1626 cases were reported as euthanasia in the sense of a physician assisting the death and 148 cases as physician assisted dying. In 2007 the total number of cases was 2120.

Of the cases in 2008 2146 were considered as euthanasia and 152 cases as physician assisted dying (by delivering drugs for example) and 33 cases as a combination of the two (5).

The family doctor is far most the physician, who applies euthanasia as is shown in Table 1 and the place of death is most frequently at home (see Table 1).

Table- 1. Physicians assisting in euthanasia and place of death in 2008 in the Netherlands (5)

<i>Medical specialist</i>	Number	<i>Place of death</i>	Number
Family doctor	2083	At home	1851
Specialist in hospital	152	Hospital	145
Nursing home specialist	91	Nursing home	87
Physician in training	5	Home for the Elderly	111
		Others (hospice/ family)	137
Total	2331		2331

The diagnosis of the patients were: 1893 cancer  
62 cardiovascular diseases  
117 neurological diseases  
145 other diseases  
114 more diseases

The regional review committees reviewed all cases. The average time between receiving the cases and finishing the review was 32 days in 2008. The review committee identified ten cases (out of the 2331), which did not meet the due care requirements. The reasons were often related to information and communication and the use of other than 'recommended drugs'.

### Discussion

The Dutch 'Euthanasia Law' is in practice now for 7 years. The legislation represents the culmination of almost thirty years of public debate in the Netherlands about legalising

euthanasia. This discussion has shown Dutch citizens are willing to discuss difficult moral issues openly and show respect for the autonomy of others. The majority of Netherlands people support voluntary euthanasia.

The Royal Dutch Medical Association has played an important role in this public debate and has approved doctors participating in termination of life on request or assisting with suicide. It is a respected task for the medical profession, within the due care requirements, and there exists a comprehensive medical coverage. Doctors in the Netherlands have been participating in euthanasia for a considerable time. Of course, doctors may refuse to commit euthanasia for personal, ethical and/or religious reasons. If so, however, the physician has the duty to inform the patient in time and to refer the patient to another physician.

The law applies only for Dutch citizens. It is not possible for people to come from other countries to seek termination of life or assistance with suicide in the Netherlands because of the legislation's procedural requirements.

The procedure for the notification and assessment of each case requires the patient to have made a voluntary, considered request and to be suffering without any prospect of improvement. In order to be able to assess whether this is the case, it is considered that the doctor must know the patient well and implies that the doctor has treated the patient for some time.

This is not to say that legalising euthanasia and physician assisted dying is a solution for all countries. In 2005 the Parliamentary Assembly of the Council of Europe rejected a draft Resolution which would have called upon Member States to legalise euthanasia.

Belgium, Luxemburg and the Netherlands are the only countries in Europe and in the world, who have legalised euthanasia. The Parliamentary Assembly of the Council of Europe, however, has adopted a resolution to stimulate palliative care in member states (6). The later indicates a discrepancy between euthanasia and palliative care.

The European Association for Palliative Care (EAPC) has stated euthanasia is not part of the responsibility of palliative care. Attention to euthanasia may distract from palliative care seems to be the fear. Will palliative care changes by regulating euthanasia (7)? Palliative care has its own merits and expertise. Research indeed indicates that palliative care and euthanasia do not affect each other (8,9). Such research may be helpful to an open debate concerning the relationship between palliative care and end-of-life decision-making. A request for euthanasia is not the consequence of a lack of access to palliative care, but a autonomous decision taking by a human being. It means that the need of euthanasia will not disappear when palliative care services are sufficiently available. However, when such services are available the choices of human beings, suffering from a terminal disease, are increasing.

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# COMMENTS, DISCUSSION

## An on-going debate: euthanasia

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In some EU countries euthanasia (like Belgium, the Netherlands) is permitted through specific legislation, i.e. specific criteria to be fulfilled and required procedures to be followed. One criterion is 'unbearable suffering'. This is not an easy criterion to apply since the first question which arises is what does 'unbearable' mean, immediately followed by the second one unbearable according to who: patient, family or doctor? And indeed, research in the Netherlands shows patients include psychological aspects as possible unbearable, while doctors consider physical aspects mainly as unbearable (1). In the Dutch legislation unbearable is not limited, however, to physical aspects. But also the law specifies 'unbearable' is not sufficient, the suffering should also be 'hopeless'.

Of course, a request for euthanasia has to be the autonomous decision of the patient, i.e. made in free will. But once, such a will is expressed the mental and health status of the patient will be assessed by a medical doctor, mostly the doctor who treats the patient. This assessment has to be controlled by another doctor, who does not treat the patient and whose situation safeguards an independent judgement. This other doctor has to meet the patient and has to present a written statement about hopeless and unbearable suffering. But what happens if during the assessment the condition or situation of the patient changes? It means 'hopeless' gets another perspective.

This 'changing perspective' is special relevant for the so-called 'declaration of intent' of a (serious) (ill) person, like a person diagnosed with dementia. When does the patients' situation become hopeless in case of dementia? Could it be the case when the patient is already wills incompetent? But does the request for euthanasia still applies in such a situation, where the patient does not act (anymore) out of free will?

A person may have discussed the possibility of euthanasia with the family doctor in case a disease like Alzheimer or Parkinson becomes a certainty. If such a diagnosis is confirmed, the patient may fear hopeless and unbearable suffering, which perspective is unacceptable and cause severe psychological suffering. Since a 'declaration of intent' is no guarantee, the patient may request for euthanasia now. Free will and wills competence are confirmed by independent assessment. What to do? Is euthanasia a 'right of the patient'? It can never be the duty of a doctor to assist in euthanasia, but should such a patient left alone?

In some countries like USA and UK, where euthanasia, i.e. physician assisted suicide, is not legalised, more and more terminal ill patients look for other methods to die. In doing so, the very ill patients may need the help of family or friend. In both countries, however, assistance to suicide is forbidden. The other solution is 'euthanasia tourism'. Patients in the USA go to Mexico, patients in the UK to Switzerland. Euthanasia tourism will become big business in ageing societies like 'transplantation tourism'. However, these 'solutions' are for the well to do.

Stimulation and availability of palliative care may be seen as the best solution to deal with hopeless and unbearable suffering. But what to do if such services are not available?

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## NEW PUBLICATION

### Coming home to go .... Palliative care in general practice

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Van Gorcum, Assen, the Netherlands, 2009

In the Netherlands 60-70% of cancer patients dies at home. The care for the terminal patient is the task of the general practitioner (GP, family doctor) in close cooperation with informal carers (mostly family members) and often supported by professional home care. This study describes how such a care process has developed during the last century. To do so, seven dissertation, written and defended between 1918 and 2006, are analysed. But also consultations by other specialists are analysed. These analyses intend to answer the question 'How can GPs be supported to optimize palliative care for patients with cancer (and other diseases) dying at home?'

Taking care at home of terminal cancer patients is often not easy. It has been the task of the GP for many years in the Netherlands. But it does not mean that GPs have the answer to all the questions, which arise in taking care for dying patients at home. Unexpected complications and severity of symptoms make additional support and expertise necessary. Therefore special consultants for the GP are available for direct telephonic consultation. The study analysed 1385 of such consultations between 2000-2003. The main outcomes are as follows:

- the majority of the GPs asked for consultation short before the patient died,
- the consultation question was mostly dealing with physical symptoms,
- the advices of the consultants were evaluated as valuable and followed in 85% of the cases,
- frequently asked questions were about nausea and vomiting and about sedation and euthanasia.

The incidence of psycho-social complaints like anxiety and depression did not increase neither was a difference found in these complaints between cancer en non-cancer patients. But that is not to say, that these complaints are not frequent neither need attention of the GP. Indeed, many patients have been found to have mental problems like anxiety and depression. And there is the danger that these symptoms are poorly recognized and therefore may be under treated.

The study concludes, that GPs perceive palliative care as an important and valuable part of primary health care. Nevertheless, they consider their coordinating role not as easy. They know that complications often occur; such complications are not only medical ones, but also psychological and social ones, including communication, defence mechanism, bereavement and ethical issues.

It is recommended to strengthen and support the GPs coordinating role in palliative care by training in more basic knowledge, skills in communication and consultation.

## NEWS

### Switzerland and assisted suicide: new legislation?

In Switzerland assisted suicide is allowed based on altruistic (unselfish) motives. Assisted suicide has been legal in Switzerland since the 1940s. It needs not be performed by a medical doctor.

In Switzerland, assisted suicide falls under Article 115 of the Swiss penal code. As such it is a crime if and only if the motive is selfish. All assisted suicides in Switzerland have to be reported. Once reported to the police, the police, an officer from the coroner's department and a doctor all attend the death. At this time family and friends are interviewed. If a selfish motive cannot be established, there is no crime.

Interestingly, Swiss law also states that the permissibility of altruistic assisted suicide cannot be overridden by a duty to save life. This safeguards those assisting in the suicide, as long as the motivation is altruistic.

Historically, the Swiss Academy of Medical Sciences considered assisted suicide not a part of a physician's activity, but in 2003 the academy advised doctors could help the terminally ill die under strict conditions.

In 2005 the Swiss National advisory Commission on Biomedical Ethics recommended that each acute care hospital should determine whether to allow assisted suicide within its walls. Since than many hospital have a institutional directive specifying the conditions for assisted suicide.

Most assisted suicide is supported by private organizations. Two organizations 'Exit' and 'Dignitas' are the most profiled, both conducting assessment and delivering lethal medication. Exit is the largest one. Dignitas was the only organization caring for foreigners till end 2008.

In 2006 the Federal Council recommended that a new legislation was not needed, but also due to international news on "Swiss suicide tourism". In October 2009 the Federal Council has drafted two options on *organized* assisted suicide.

Essentially, the Federal Council does not wish to take anything away from the current, liberal legislation, which permits someone to assist a suicide provided they are not motivated by their own interests.

Since *assisted suicide organizations* are increasingly testing the boundaries of the law, the Federal Council sees a need to specify guidelines and restrictions. These should prevent organized assisted suicide becoming a profit-driven business. They should also ensure that assisted suicide is available to terminally ill patients only, remaining closed to those with a chronic or mental illness. Also the Council underlines the importance of palliative care and suicide prevention.

The two options proposed are 'strict duties of care' and 'ban on organized assisted suicide'. The first option '*strict duties of care*' employees of assisted suicide organizations would be committing a criminal offence unless it can be proven that they have observed all of the duties of care laid down in the Penal Code (free choice, time and proper consideration). New is that two certificates from two different doctors who are independent of the assisted suicide organization are needed. One of the certificates must attest that the suicidal person has the legal capacity to decide for themselves. The other must state that the suicidal person suffers from a physical illness that is incurable and will result in death within a short period.

Furthermore, those assisting a suicide must discuss and examine alternatives to suicide with the person concerned. The drug that is used must have been prescribed by a doctor. This demands that a diagnosis and the corresponding indications be established in accordance with the physician's professional obligations and duties of care. Those assisting a suicide may not accept any payment for their services that would exceed the costs and expenses of the assisted suicide. Finally, the assisted suicide organization and those who actually assisted the suicide must document each case comprehensively in order to help any enquiries on the part of the criminal prosecution authorities.

The second option "*ban on organized assisted suicide*" is a complete ban on organized assisted suicide. This option rests on the belief that individuals working in assisted suicide organizations are never actually motivated by purely altruistic reasons. It is up to the Swiss parliament to decide whether legislation should be adapted and on which way.

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