

Quelques points de vue internationaux relatifs à la fin de vie

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Self-determination and care at the end of life, German national ethics Council, July 2006

The predominant position of the members of the National Ethics Council is that there are fundamental objections to any form of organized provision of assisted suicide, because it confers the appearance of normality on acts directed towards the extinction of an individual's own life. This would substantially lower the threshold established by society's taboo on the taking of one's own life that deters potential suicides from acting in accordance with their mental state. If the public activity of organizations whose sole or principal purpose is to facilitate suicide meets with social and cultural acceptance or is even merely tolerated, society, according to this view, can no longer appropriately perform its function of protecting persons at risk of suicide. Admittedly, in certain circumstances a request for help with suicide made on the basis of clear and free volition and in an unequivocal crisis situation of distress (illness) may mitigate the moral disapproval of such assistance or, in an extreme case, overcome it altogether. However, such assistance should then be rendered at most by close friends or relations, but not by organizations.

7.2 End-of-life care and therapies at the end of life

1. Every incurably ill and dying individual is entitled to be treated, nursed and cared for with dignity.
2. The wishes of the person concerned must be respected in all end-of-life measures and therapies at the end of life.
3. Every incurably ill and dying individual must be provided with adequate palliative care. For this purpose, doctors should be able without fear of prosecution to accord priority to the patient's quality of life over maximizing the length of his life.
4. Adequate inpatient and outpatient care in nursing homes, palliative wards and hospices is urgently necessary.
5. The provision of interdisciplinary training and Advanced training for doctors and nurses treating seriously ill and suffering patients and the dying should be increased.
6. Voluntary commitment to end-of-life care should be promoted and supported.
7. Family members should have access to skilled counselling on the availability of nursing and other care for the seriously ill.
8. The labour laws should provide for an entitlement to leave, so as to allow those close to a dying person to care for him, as is already the case in some other European countries.

7.3. Letting die

1. Every patient has the right to decline a medical measure. This applies even if the medical measure might prolong his life.
2. For this reason, doctors, nurses and family members should be able to withhold, limit or withdraw life-sustaining measures in accordance with the patient's wishes without fear of penal or professional sanctions.
3. The same applies if the patient is incapable of giving expression to his wishes but his rejection can be inferred with sufficient certainty from an advance directive or other reliable indication (see the National Ethics Council's Opinion on the advance directive).
4. Where there are no reliable indications of the patient's wishes or no such wishes can be formed, criminal and Professional sanctions should not be imposed if medical treatment is no longer indicated having regard to the prospects of its success, the suffering of the patient and his likely life expectancy and the treatment is therefore withheld, limited or withdrawn.
5. The preservation of life must take precedence in cases of doubt.

7.4. Suicide, suicide intervention and assisted suicide

1. Both the law and the practice of society should continue to be directed towards dissuading even the seriously ill from taking their own lives and towards offering them prospects for living.

2. If there are clear indications that a suicide attempt by a seriously ill person was made on the basis of a seriously deliberated decision and that the person concerned would refuse any measure to save his life, then, in the view of the majority of the members of the National Ethics Council, persons such as doctors or family members who have particular responsibility for the individual concerned should be able to abstain from intervening without fear of prosecution. Some members of the National Ethics Council consider it necessary to restrict this possibility to situations where the serious illness is expected to lead to imminent death.

3. Attempted and assisted suicide do not incur criminal sanctions in Germany. This should continue to be the case, although assisted suicide should be subject to the following restrictions:

3.1 Opinions within the National Ethics Council diverge on the permissibility of physician-assisted suicide: A number of members hold that physician-assisted suicide is inconsistent with the medical ethic and therefore hold that it should not be permitted by the relevant Professional code. Other members, however, believe that doctors should be able to help a patient to commit suicide if his suffering is unbearable and incurable, he is mentally competent, and his wish to die – after counselling and a sufficient period for reflection – must be deemed final.

3.2 The members of the National Ethics Council also differ on the permissibility of organized assisted suicide: The majority reject the introduction of any organized provision of assisted suicide in Germany. They consider that, depending on the circumstances, this should be made a criminal offence. A few members hold that organized assisted suicide should be permissible in Germany as in some other countries provided that certain conditions, such as counselling and a period for reflection, are satisfied. In the opinion of a small number of members, this should at least be the case as long as doctors are prohibited by professional ethics or their professional code from assisting suicide.

3.3 The National Ethics Council unanimously favours a ban, backed by penal sanctions, on assisting suicide for profit.

4. The National Ethics Council considers instigation to suicide to be ethically repugnant.

7.5. Killing on request

Killing on request should remain a criminal offence (cf. Section 216 of the Penal Code).

To allow for cases where a person, acting in accordance with the dictates of conscience, kills another at the latter's request, an explicit statutory exception to the prohibition should not be made, but no punishment should be imposed, in view of the balancing by the person concerned of the preservation of life against the ending of suffering.

Le testament de vie, German national ethics Council, Juin 2005

IV. Recommandations

1.

Le Conseil national d'éthique insiste sur le fait que la discussion concernant la portée et la force obligatoire des testaments de vie ne doit pas conduire à remettre en question l'interdiction de l'euthanasie active (article 216 du Code pénal allemand).

2.

Le Conseil national d'éthique est d'avis qu'une personne capable de décider doit avoir le droit, pour le cas de sa propre incapacité future de prendre des décisions, de se prononcer, dans des directives anticipées ou dans un testament de vie, pour ou contre un traitement médical ultérieur. Ces directives devraient également pouvoir inclure l'exécution, l'interruption ou l'abstention de mesures médicales indiquées pour le maintien en vie, mais toutefois en aucun cas des mesures d'euthanasie active. Les conditions et la portée d'un testament de vie devraient faire l'objet d'une réglementation légale dans l'intérêt de la sécurité juridique. En même temps, les efforts visant à garantir des offres de soutien en matière de médecine palliative, de traitement de la douleur, de soins aux malades et d'aide psychosociale doivent être poursuivis et renforcés.

Le testament de vie influe sur le rapport juridique du patient au médecin, au personnel soignant, au représentant ou aux parents. Il s'agit donc d'une matière qui devrait être réglementée par le Code civil. Les membres du Conseil national d'éthique considèrent une réglementation complémentaire dans le Code pénal comme souhaitable, afin de parvenir également du point de vue pénal à une plus grande sécurité juridique pour l'ensemble des personnes mentionnées, ainsi qu'à une démarcation suffisante par rapport à l'euthanasie active. Certains membres considèrent une telle réglementation dans le Code pénal comme nécessaire.

4.

Le Conseil national d'éthique est majoritairement de l'avis que le législateur devrait indiquer clairement qu'un testament de vie, à l'aide duquel une personne a pris une décision reconnaissable et suffisamment concrète concernant un traitement médical, s'impose au médecin et au personnel soignant.

Certains membres refusent une force obligatoire stricte des testaments de vie, afin de ménager aux médecins et au personnel soignant des marges de décision personnelle, pour l'utilisation desquelles ils doivent faire valoir des raisons importantes.

5.

Le Conseil national d'éthique est très majoritairement de l'avis que la

portée et la force obligatoire des testaments de vie ne devraient pas être limitées à certaines phases de la maladie.

Certains membres estiment que des déclarations relatives à l'interruption de mesures nécessaires au maintien en vie ne devraient être considérées comme ayant force obligatoire que dans le cas d'une évolution irréversible de la maladie, conduisant au décès dans un délai prévisible.

6.

Le Conseil national d'éthique recommande que simultanément à la réglementation des testaments de vie soient précisées par voie législative les compétences des curateurs et des mandataires.

Le législateur devrait disposer qu'une personne mandatée par l'intéressé ou un curateur désigné par le tribunal doit faire valoir les modalités thérapeutiques choisies dans le testament de vie du patient, contre l'avis des médecins et des personnels soignants, ainsi que des parents le cas échéant.

7.

Le Conseil national d'éthique estime majoritairement que le testament de vie, à l'aide duquel le patient a pris une décision personnelle de façon reconnaissable et suffisamment concrète concernant la situation qui se présente, a force obligatoire pour le curateur ou le mandataire et ce, même quand aux yeux de ceux-ci cette décision ne correspond pas au bien-être du patient.

8.

Le Conseil national d'éthique recommande de prévoir la compétence du tribunal des tutelles dans le cas où il existe des indices d'utilisation abusive du testament de vie par le mandataire ou par le curateur.

Le législateur devrait en outre disposer que les décisions du curateur nécessitent l'autorisation du tribunal des tutelles, lorsque lors de la reconnaissance et de l'interprétation du testament de vie, il apparaît des divergences d'opinion entre le curateur, le médecin, un membre du personnel soignant ou un parent.

9.

Le Conseil national d'éthique recommande de fixer des règles différentes concernant les compétences de décision respectives du mandataire et du curateur pour le cas où il n'existe pas de directives du patient portant sur ce sujet.

Dans ce cas, le bien-être de la personne sous curatelle devrait s'imposer légalement au curateur, conformément à la volonté présumée de l'intéressé. Pour toutes les décisions associées à un risque de décès ou d'un dommage grave et prolongé pour la santé de la personne sous curatelle, le curateur devrait avoir obligation d'en demander l'autorisation au tribunal des tutelles.

Les pouvoirs de décision du mandataire devraient en revanche découler du mandat et des marges de décision qu'il confère. Le tribunal des tutelles ne devrait être saisi que lorsqu'il existe des indices indiquant que le mandataire outrepassé les marges de décision qui lui sont accordées.

10.

Le Conseil national d'éthique est d'avis que le législateur devrait poser comme condition à la validité du testament de vie que celui-ci soit établi sous forme écrite ou sous forme de document présentant une fiabilité comparable (p. ex. un enregistrement vidéo). Les souhaits exprimés sous une forme ne répondant pas à ces exigences doivent être pris en considération lors de la recherche de la volonté présumée.

11.

Le Conseil national d'éthique estime majoritairement qu'il ne faudrait pas faire dépendre la validité d'un testament de vie du fait qu'il ait été précédé d'informations médicales spécialisées.

Tous les membres du Conseil national d'éthique recommandent cependant de faire appel à une consultation spécialisée avant de rédiger un testament de vie.

12.

Le Conseil national d'éthique recommande de veiller à actualiser le testament de vie.

Il est majoritairement d'avis qu'il ne faut faire dépendre la validité d'un testament de vie ou d'un mandat ni de délais prédéterminés, ni d'une confirmation renouvelée. Il se prononce en faveur d'une présupposition établie légalement que la décision prise dans le testament de vie ou dans le mandat doit encore valoir dans la situation concrète. La simple supposition d'un changement de volonté intervenu entre-temps ne suffit pas à réfuter la présupposition.

Certains membres pensent que lors de l'application du testament de vie ou du mandat, il faut vérifier que la volonté qui y est exprimée correspond encore à la volonté présumée du patient au moment présent.

13.

De l'opinion du Conseil national d'éthique, le législateur devrait établir clairement, en particulier eu égard au nombre croissant de maladies démentielles, que des signes de volonté de vivre d'une personne incapable de prendre des décisions annulent la force obligatoire d'un refus de soins contenu dans un testament de vie, à moins que:

- a. la situation médicale dans laquelle une décision est à prendre ne soit décrite de manière suffisamment concrète dans le testament de vie,
- b. le testament de vie ne fasse référence aux signes mentionnés de volonté de vivre et n'exclue leur pertinence pour la décision à prendre,
- c. le testament de vie ne soit rédigé par écrit ou documenté sous une forme présentant une fiabilité comparable, et que
- d. la rédaction du testament de vie ait été précédée d'une consultation spécialisée appropriée.

14.

L'existence ou l'absence d'un testament de vie ne doit devenir une condition de l'accès aux établissements de soins. Les testaments de vie ne doivent pas non plus faire l'objet d'une utilisation abusive d'une quelconque autre manière à des fins économiques.

End-of-life décisions, views of the BMA, British Medical Association, 2009

Advance refusals and requests

There is also separate BMA guidance on *Advance decisions and proxy decision-making in medical treatment and research*. Advance decisions allow competent adults to say what they would like to happen later if their mental capacity becomes impaired. These decisions become important once patients lose their mental capacity, are unconscious, or unable to communicate. Also known as a living will, advance decisions can request or refuse future treatment. Subject to certain criteria being met, refusals are legally binding. Even advance decisions that fail to meet the legal criteria can provide some insight into the patient's thinking and be helpful in indicating what is in the individual's best interests.

In England and Wales, advance decisions are covered by the Mental Capacity Act. To be valid and legally binding the advance decision must be specific about the treatment that is being refused and the circumstances in which the refusal will apply. Where the patient's advance décision relates to a BMA Ethics End-of-life décisions refusal of life-prolonging treatment this must be recorded in writing and witnessed. Patients must be explicit that they intend to refuse treatment even though this puts their life at risk. In Scotland and Northern Ireland, advance decisions are not covered by statute but by common law.

An advance refusal of treatment is likely to be binding in Scotland and Northern Ireland if the patient was an informed and competent adult at the time the decision was made (16 years old in Scotland and 18 in Northern Ireland).

The advance decision may be open to question if the circumstances that have arisen since the patient's loss of mental capacity are radically different to those that the individual had envisaged. Therefore, doctors need to consider whether the advance decision fits the current situation or if it differs significantly from the scenario the patient anticipated. Advance refusals made in the distant past and not updated are not necessarily invalid but if treatment options have substantially altered, its validity may be questioned. Doubts about validity can also arise if it appears that individuals already had impaired capacity at the time of making the decision. Or if evidence suggests that they lacked significant information or were subject to coercion when deciding. In case of doubt, legal opinion should be sought.

If an advance refusal of treatment appears valid and is applicable to the current circumstances, health professionals must abide by it. Patients

cannot demand or refuse anything in advance that they cannot demand or refuse when conscious and competent. Therefore, patients cannot refuse in advance compulsory treatment provided under the mental health legislation or demand euthanasia or assisted dying. Also although advance requests or authorisation of specific treatment can be helpful, they lack legal weight if clinicians assess that treatment to be inappropriate.

Advance decisions have some advantages in terms of encouraging openness, dialogue and forward planning. They also have potential disadvantages as they cannot encompass unforeseen possibilities and options. Treatment decisions are often complex and treatment techniques evolve. Advance decisions made long before capacity is lost can fail to reflect how treatment options have changed.

Patients' views can also change and the onus is on the individual, while competent, to ensure that their recorded views continue to match their current wishes.

Withholding and withdrawing life-prolonging medical treatment

Medical treatment can legally and ethically be withdrawn when it is unable to benefit the patient. It should be withdrawn when it is not in the patient's best interest or if the patient has refused it.

In practice, however, this is, a profoundly difficult decision. This was illustrated in 1993 by the House of Lords deliberations in the case of Tony Bland. In a persistent vegetative state (PVS) with no awareness of the world and no hope of recovery, Bland was not terminally ill but withdrawal of artificial nutrition would inevitably result in his death. Following judgments made in other jurisdictions and confirming that artificial nutrition constitutes a medical treatment, the House of Lords agreed that it could be withdrawn.

Medicine aims to restore or maintain patients' health by maximising benefit and minimising harm.

When medical treatment ceases to provide a net benefit to the patient, this primary goal of medicine cannot be realised and the justification for intervening is gone. Unless some other justification can be demonstrated, most people would accept that treatment should not be prolonged. The BMA does not believe that it is appropriate to prolong life at all costs, with no regard to its quality or the burdens of the intervention.

Technological developments continually extend the range of treatment options available to prolong life when organ or system failure would naturally result in death. Patients with progressive, dégénérative conditions can have their lives prolonged considerably but this will not necessarily reverse a patient's disease. Other patients, for example those with very severe brain damage, may remain stable for many years if life-prolonging treatment is provided, but this may be with no hope of recovering more than very minimal levels of awareness of their surroundings. They may lack the ability to interact with others or the capacity for self-directed action. In such severely damaged patients,

treatment or intervention to prolong life by artificial means may fail to provide sufficient benefit to justify the intervention and the proper course of action may be to withhold or withdraw further treatment.

The guiding principles underlying any such decision must be to protect the dignity, comfort and rights of the patient; to take into account any known wishes of the patient and the views of people close to patients who lack capacity. Communication and consultation are essential. A thorough clinical evaluation, including the initiation of treatment for a trial period if appropriate, should take place, so that the decision is based on as accurate as possible an assessment of the benefits, risks and burdens of the treatment for that particular patient. Where the treatment to be withheld or withdrawn is artificial nutrition and hydration, a second clinical opinion should be sought before treatment is withdrawn or withheld from a patient who is not imminently dying. Furthermore, in England, Wales and Northern Ireland, the withdrawal or withholding of ANH from a patient in a persistent végétative state needs to be subject to court review. In Scotland, this is not obligatory but it is advisable to seek legal advice.

The BMA's guidance, contained in *Withholding and withdrawing life-prolonging medical treatment*, gives advice on the ethical, legal and clinical issues, and sets out safeguards for decision-making. It indicates how the human rights legislation applies in this area. It also seeks to provide a coherent and comprehensive set of principles that apply to all decisions to withhold or withdraw life-prolonging treatment, which it is hoped will stimulate the development of local policies and guidelines. The General Medical Council has consulted on proposed revisions to its guidance on the same topic. For further information, see the GMC's website.

Doctors considering withholding or withdrawing life-prolonging treatment can find detailed guidance in the BMA book. In any cases of doubt, legal advice should be sought. In cases where the patient is an incapacitated adult, advice can be sought in England and Wales from the Official Solicitor. Northern Ireland has its own Official Solicitor to act on behalf of mentally incapacitated people. In Scotland, advice can be sought from the Mental Welfare Commission or NHS Central Legal Office.

Assisted dying

'Assisted dying' covers euthanasia (where someone other than the patient administers a fatal dose) and assisted suicide (where patients are assisted to end their own lives).

Traditionally, the BMA opposed any form of assisted dying, but in 2005 its ARM (its policy-making body) recognised that there were diverse opinions within society and the profession. It agreed that

Parliament and society at large should decide the issue of possible legalisation. This meant that the BMA took a neutral stance on assisted dying. In 2006, however, BMA members voting at the ARM made clear that the majority opposed such legislation. Therefore the BMA dropped its

neutral stance and again opposes all forms of assisted dying.

The current policy is that the BMA:

- (i) believes that the ongoing improvement in palliative care allows patients to die with dignity
- (ii) insists that physician-assisted suicide should not be made legal in the UK
- (iii) insists that voluntary euthanasia should not be made legal in the UK
- (iv) insists that non-voluntary euthanasia should not be made legal in the UK; and
- (v) insists that if euthanasia were legalised, there should be a clear demarcation between those doctors who would be involved in it and those who would not.

This was reiterated in 2009 when the BMA's ARM rejected a proposal to change the law and allow competent, terminally ill patients to choose assisted dying. It also voted against legal immunity for people who accompany patients to an assisted death abroad.

Euthanasia

Euthanasia which is the active and intentional termination of a person's life remains illegal in the UK. It is morally and legally different to the withholding or withdrawal of treatment. Arguments for legalisation of euthanasia are generally based on arguments about competent individuals' rights to choose the manner of their demise or about cases where medicine is unable to control distressing terminal symptoms. Although the BMA respects the concept of individual autonomy, it argues that there are limits to what patients can choose if their choice will impact on other people.

Arguments against legalisation often focus on practical points. If euthanasia were an option, there might be pressure for all seriously ill people to consider it even if they would not otherwise entertain such an idea. Health professionals explaining options for the management of terminal illness would have to include an explanation of assisted dying. Patients might feel obliged to choose it for the wrong reasons, if they were worried about being a burden, or concerned about the Financial implications of a long terminal illness. Legalisation could generate anxiety for vulnerable, elderly, disabled or very ill patients.

Physician-assisted suicide

Aiding or abetting suicide is also illegal and carries a potential 14-year sentence. The arguments for and against assisted suicide and physician-assisted suicide are similar to those made in relation to euthanasia. Assisted suicide differs from euthanasia in that the individual retains control of the process, rather than the doctor or anyone else assisting. In its early policies, however, the BMA did not distinguish between euthanasia and physician-assisted suicide. In 1997, BMA policy mentioned

both for the first time and while recognising that a diversity of opinion existed about them, opposed any changes in law to permit either.

In 1998 the BMA Medical Ethics Department published a discussion paper debating whether the moral arguments about physician-assisted suicide and euthanasia differ significantly. The BMA's ARM also called for a conference 'to promote the development of a consensus on physician-assisted suicide'.

This took place in March 2000, resulting in a consensus statement opposing physician-assisted suicide.

End of life care strategy, Departement of Health, July 2008

Aim of this end of life care strategy

1.33 In the past, the profile of end of life care within the NHS and social services has been relatively low. Reflecting this, the quality of care delivered has been very variable. The aim of this strategy is to bring about a step change in access to high quality care for all people approaching the end of life. This should be irrespective of age, gender, ethnicity, religious belief, disability, sexual orientation, diagnosis or socioeconomic status. High quality care should be available wherever the person may be: at home, in a care home, in hospital, in a hospice or elsewhere. Implementation of this strategy should enhance choice, quality, equality and value for money.

1.34 This aim can be achieved through the following ten objectives:

LL To increase public awareness and discussion of death and dying. This will make it easier for people to discuss their own preferences around end of life care and should also act as a driver to improve overall service quality;

LL To ensure that all people are treated with dignity and respect at the end of their lives;

LL To ensure that pain and suffering amongst people approaching the end of life are kept to an absolute minimum with access to skilful symptom management for optimum quality of life;

LL To ensure that all those approaching the end of life have access to physical, psychological, social and spiritual care;

LL To ensure that people's individual needs, priorities and preferences for end of life care are identified, documented, reviewed, respected and acted upon wherever possible;

- LL To ensure that the many services people need are well coordinated, so that patients receive seamless care;
- LL To ensure that high quality care is provided in the last days of life and after death in all care settings;
- LL To ensure that carers are appropriately supported both during a patient's life and into bereavement;
- LL To ensure that health and social care professionals at all levels are provided with the necessary education and training to enable them to provide high quality care; and
- LL To ensure that services provide good value for money for the taxpayer.

All people approaching the end of life, and their carers, should be entitled to:

- LL Have their needs assessed by a professional or professionals with appropriate expertise;
- LL Have a care plan which records their preferences and the choices they would like to make. The care plan should be reviewed as their condition changes;
- LL Be involved in decisions about treatments prescribed for them, including the option to say 'no' to treatments they do not wish to have prescribed; and
- LL Know that systems are in place to ensure that information about their needs and preferences can be accessed by all relevant health and social care staff with their permission.

3.38 Those who assess patient and carer needs should have reached an agreed level of competence in aspects of the assessment process. They should also have access to up to date information about local service providers, referral criteria and support services.

3.39 Care plans, including the person's preferences, wishes and views on resuscitation, should be available to all who have a legitimate reason to access them, including out of hours and emergency/urgent care services. Holding the plan electronically will facilitate this. All care plans should be regularly reviewed and updated.

Dementia : ethical issues, Nuffield Council on bioethics, 2009

End of life palliative care

3.39 NICE has recommended that a palliative care approach, considering a person's "physical, psychological, social and spiritual needs", should be adopted from diagnosis to death, and that people with dementia should have the same access to palliative care services as others. The importance

of access to appropriate end of life care for people with dementia has also been emphasised in the English dementia strategy, the Scottish dementia priority paper and the draft action plan for Wales, and in the English and Scottish end of life strategies. We have already discussed in paragraphs 3.8 and 3.9 how the concept of 'supportive care' seeks to avoid a sharp distinction between 'active treatment' and 'palliative care' by emphasising the individual's need for ongoing physical, psychological, social and spiritual care, regardless of the existence (or absence) of any form of therapy targeted at the underlying disease. In this section, we will therefore use the term 'palliative care' to refer to the specific care needs which arise at the very end of life. As such, it can be regarded as one component of supportive care.

3.40 As the recommendation from the NICE/SCIE guidelines, cited above, implies, there is a growing awareness of the inadequacy of current palliative care support for people with dementia, and the need to take action to ensure that appropriate services become available. It should be noted that, at present, there is only limited evidence for the effectiveness of traditional palliative care models in dementia. It may be harder to identify when the person with dementia is truly reaching the end of their life; some of the skills involved in providing specialist end of life care to people with dementia may differ from those developed in the context of cancer; moreover, as many people with dementia will already have moved from their own homes into a care home, a further move into the new environment of a hospice would not usually be appropriate.

3.41 Nevertheless, there *is* evidence that people with dementia experience poor care at the end of their lives, with badly controlled pain, little control over the place and manner of their death, and significant stress on their carers. Moreover, recent research in the UK has suggested that amongst older people who die in hospital, those who have dementia are less likely to receive palliative medication, are less likely to have attention paid to their spiritual needs, and are less likely to be referred to palliative care specialists than people who do not have dementia.

3.42 There is further concern that many people with dementia are fed inappropriately through a tube at the end of their lives, without proper consideration being given as to possible alternatives or to the effect on the individual. The National Council for Palliative Care, for example, highlights that current evidence supports "careful hand feeding" as being the feeding method of choice for people with advanced dementia, especially given the benefits of additional human contact and social interaction; and encourages those considering tube feeding to think carefully in each case about what it is that they are hoping to achieve, given the terminal nature of end-stage dementia; what the person would have wanted; and what action would genuinely be in the person's best interests. This issue was picked up in the English dementia strategy, which cited a 2004 report of people with dementia dying "with inadequate pain control, with feeding tubes in place, and without the benefits of hospice care", as an example of the need for significant improvement.

3.43 It is clearly imperative that key elements of the palliative care approach – in particular the focus on caring for the ‘whole person’, the importance of advance care planning (see Chapter 5), the provision of adequate pain relief, the avoidance of inappropriate treatment, and support for family – should be made available in an appropriate way to people who are dying with dementia. One reason put forward as to why people with dementia have traditionally not been able to access hospice care is the simple fear that including people with dementia might overwhelm existing services or make them unaffordable. While this concern may be quite understandable at the level of individual small services struggling to survive on charitable funding, such an attitude within the wider NHS is completely inconsistent with the equal value to be placed on people with dementia and the importance to be placed on consideration of their interests.

3.44 As the 2008 National Audit Office report on end of life care makes clear, palliative care services are increasingly being delivered in a variety of environments outside hospices, including in hospitals, care homes and people’s own homes, with palliative care specialists working in partnerships with other health and social care professionals such as GPs and district nurses. It seems highly likely that ‘partnership working’ of this kind will be the way forward to ensuring that the benefits of specialist palliative care are made available to people with dementia and their families. Indeed, in January 2008 and again in February 2009, the National Council for Palliative Care published practical guidance on developing partnership-based approaches to palliative care for people with dementia, based on a number of case studies and commentaries by professionals from different disciplines.

Examples cited include the ‘Croydon project’, where specialists from St. Christopher’s Hospice in London provide both training and supervision within nursing homes to enable nursing home staff to develop palliative care skills; and a partnership between ‘Housing 21’ supported housing and Macmillan nurses to provide end of life care to a woman with dementia who also had terminal liver cancer and wished to remain in her own extra-care home. In Scotland, the ‘Beyond Barriers’ project has similarly sought to develop current care practice in care homes by supporting both staff and relatives to meet the palliative care needs of people in the later stages of dementia.

3.45 We note, and welcome, the fact that the English dementia strategy, the Scottish dementia priority paper, and the draft action plan for Wales all identify end of life care for people with dementia as an important target for improvement, and that the various UK end of life strategies similarly recognise the particular needs of people with dementia. It is clear that a key factor will be the development of models of end of life care which are appropriate to dementia, and we welcome the English dementia strategy’s commitment to the development and evaluation of such models. We also strongly agree with the National Council for Palliative Care that

close working locally between those responsible for dementia care and those responsible for end of life care is absolutely crucial: neither will be fully effective without the other.

3.46 An inevitable aspect of end of life care concerns decisions as to when it may be appropriate *not* to provide a particular treatment for the dying person and how best to manage symptoms, particularly pain, at the very end of life. Such decisions are often difficult, even when there is no real clinical doubt as to the appropriateness of the decision. Staff at the specialist dementia home Vale House, for example, cited the situation when a person with dementia definitively stops eating, and where attempts to encourage continued eating fail, as a particularly difficult ethical dilemma, even though in such circumstances it is widely accepted that tube feeding is not appropriate, and death is inevitable. Professional guidance and literature in this area draw a distinction between feeding difficulties because of dementia, which require a gentle and largely palliative approach, and feeding difficulties caused by other illnesses affecting the person with dementia, which may sometimes require short-term artificial nutritional support.

3.47 We discuss in more detail in Chapter 5 how a person's earlier wishes and decisions about their health care should be considered and balanced with any preferences conveyed (for example through behaviour or gesture) after the person has lost the legal capacity to make such decisions. We note here, however, that our focus on the value of the person with dementia, and the importance of both their autonomy and their well-being, make very clear that a decision to cease active treatment (for example withholding antibiotics that may possibly cure a chest infection) should not be made on the premise that a life with dementia is not worth living. Rather, in such cases, the benefits and burdens of treatment for *this* particular person must be considered.

Quatrième rapport aux chambres législatives, Commission fédérale de contrôle et d'évaluation de l'euthanasie, année 2008 et 2009.

Résumé et conclusions

1. Le nombre d'euthanasies déclarées a été pendant les années 2008 et 2009 en moyenne de 63 par mois. Comme antérieurement, la grande majorité des documents d'enregistrement sont rédigés en néerlandais. L'augmentation du nombre d'euthanasies par rapport au rapport précédent était prévisible et s'explique vraisemblablement par la diffusion progressive de l'information relative aux décisions en fin de vie auprès du public et des médecins.

2. Les affections à l'origine des euthanasies ont toutes été, comme l'exige

la loi, incurables et graves, sans issue médicale possible. Dans la très large majorité des cas, il s'agit de cancers généralisés ou gravement mutilants chez des patients dont le décès est attendu à brève échéance et, dans une moindre mesure, d'affections neuromusculaires évolutives mortelles. D'autres pathologies sont rarement en cause. Parfois, la gravité de la pathologie ou le caractère insupportable des souffrances résulte de la coexistence de plusieurs pathologies incurables. Chez les patients d'âge avancé, la distinction qui doit être faite entre les souffrances liées à ces pathologies et celles qui sont propres à l'âge a parfois donné lieu à des divergences de vues entre la majorité de la commission et certains de ses membres. Les euthanasies pratiquées lorsque le décès n'est pas attendu à brève échéance sont relativement rares et concernent essentiellement des affections neuromusculaires évolutives mortelles avec tétraplégies ou paralysies graves multiples, et exceptionnellement des séquelles neurologiques graves consécutives à une affection pathologique ou à un accident.

3. Les souffrances insupportables et inapaisables dont font état les patients sont souvent multiples et concernent généralement à la fois les sphères physique et psychique. Comme mentionné plus haut, certains membres ont exprimé à l'égard de quelques déclarations une réserve quant à l'interprétation par la commission de la notion de « souffrance psychique insupportable et inapaisable ».

4. La majorité des euthanasies ont été pratiquées chez des patients d'âge moyen; les euthanasies sont peu fréquentes en deçà de 40 ans et au-delà de 80 ans.

5. 44% des euthanasies se pratiquent au domicile du patient et 8% en maison de repos ou de repos et de soins. La proportion des euthanasies pratiquées à la résidence du patient est donc plus élevée que dans le précédent rapport.

6. 36 euthanasies ont été pratiquées chez des patients inconscients sur la base d'une déclaration anticipée. Ce nombre reste faible en raison du champ d'application limité de cette déclaration, puisqu'elle ne concerne que les patients irréversiblement inconscients. Plusieurs Membres de la Commission estime que les procédures de rédaction, de renouvellement et d'enregistrement de la déclaration sont inutilement lourdes et devraient être simplifiées.

7. Dans la très grande majorité des cas, l'euthanasie est pratiquée correctement et en accord avec les données disponibles de la littérature médicale, en induisant d'abord une inconscience profonde; dans tous les cas où un commentaire accompagne la technique utilisée, il signale que le décès survient paisiblement en quelques minutes, fréquemment en présence de proches.

8. Aucune déclaration n'a mis en évidence de violation des conditions de fond de la loi. Les erreurs d'interprétation, qui ne portent que sur des points de procédure, sont rares et ont été résolues sans difficulté majeure.

The History of Euthanasia Debates in the United States and Britain, Ezekiel J. Emanuel, MD, PhD, 15 November 1994, *Annals of Internal Medicine*, Volume 121, Number 10

Conclusion

We are in the midst of a deep battle over the legalization of euthanasia, a battle that has profound implications for the care of the terminally ill and aged and the social understanding of medicine. This is not the first time that this battle has been waged in Britain and the United States; we have largely forgotten the exuberant euthanasia debates that occurred between 1870 and 1936 in both countries. Remembering those debates and trying to identify common threads among them may help us gain a more enlightened perspective on our current concern with euthanasia.

It seems clear that the arguments for and against euthanasia have changed neither in form nor substance in almost 120 years. They predate by many decades those arguments made in Nazi Germany, and they appeal to various philosophical traditions. This history suggests that factors other than technology play a critical role in making people receptive to euthanasia. In trying to identify general patterns that might explain public interest in euthanasia in the United States and Britain, the resurgence of individualistic conservatism, characteristic of both the Gilded Age and the Reagan-Thatcher years, is striking, as is the waning of interest in euthanasia in the early 20th century when this individualistic public philosophy was repudiated by Progressivism. It is also striking that British and U.S. interest in euthanasia flourished at the two times in the last century when the struggle over physician authority was most pronounced. Such connections raise important questions about what forces are driving our current interest in euthanasia and whether there are alternative ways to achieve a compassionate and painless death.

Palliative care for older people, better practices, World Health Organization, Europe, 2011

Policy-makers and decision-makers should do the following.

1. Recognize the needs

- a. Recognize the public health implications of ageing populations with palliative care needs and that substandard care towards the end of life is a public health problem.
- b. Identify and support older people with palliative care needs in various settings, including the community, nursing homes and hospitals, including intensive care.

2. Develop a strategy

a. Develop, invest in and implement a palliative care strategy that includes specifically the needs of older people in relation to all diseases and the insights and practice of modern care of older people (geriatric medicine, geriatric nursing and mental health services for older people) and dementia care.

b. Monitor the success of the strategy, Learning from examples in other countries.

c. Ensure a systems-wide approach and develop palliative care for older people as part of the whole health care service.

d. Embrace and invest in the needs of people with diseases other than cancer, recognizing issues of multiple morbidity and long-term conditions.

3. What the strategy should include

a. Building knowledge and development

- Develop national strategies for palliative care research that are formally linked with geriatrics and expand investment in this area across all diseases.

- Include evaluation as a key outcome that health professionals consider routinely. This involves investing in audit and quality improvement methods to improve the care provided for local populations and rewarding the health organizations, including nursing homes, involved in auditing and quality improvement schemes.

- Develop national data sets for palliative care.

- Facilitate change by supporting demonstration projects.

- Ensure that, when developments or new services are planned, evaluation is an integral part of this.

b. Education and awareness

- Promote and invest in developing palliative care skills among staff working across all settings.

- Ensure that the training of health care professionals includes sufficient time devoted to palliative medicine, geriatric medicine, geriatric nursing and mental health services for older people and that professionals are supported in keeping up to date.

- Promote public awareness of palliative and end-of-life care so that these issues can be more openly discussed and there is greater awareness of what good care can achieve. One way to achieve this is by including a component of public education in public health policies beyond traditional adult education courses to reach people from a wide range of communities using a variety of media.

- Ensure that palliative care is a core part of the training and continuing professional education of doctors, nurses, social workers, chaplains and other health professionals.

c. Providing care and services

- Use the examples in this booklet to locally adapt and invest in specific initiatives to improve palliative care for older people in all settings.

- Recognize the work of families and caregivers and invest in support to help them care for older people reaching the end of life.

- Invest in services based on need in terms of symptoms and problems and their effectiveness in meeting that need rather than on diagnosis.
- Encourage health service providers to ask people about their preference for place of care and death. Meeting individual preferences should be the ultimate measure of success.
- Ensure that multidisciplinary services shown to meet the needs of older people for palliative care are adequately funded, rewarded and supported.
- Demand and invest in high standards in palliative care for older people, including pain and symptom management, communication skills and coordination of care.
- Ensure that interventions are multifaceted and integrated within the health system.

Those involved in the national, régional and local planning of health care should do the following.

1. Guide planning, legislation and regulation of palliative care for older people (at the national level) in conjunction with the specialist care of older people. The national administration should be responsible for setting defined priorities on allocating scarce resources.
2. Allocate resources to priorities set by the national administration, so that national standards are adapted to meet local needs, establishing regional guidelines for palliative care for older people (district or regional management).
3. Invest in research, development and éducation as part of the overall strategy on palliative care for older people.
4. Plan palliative care for older people at the level of local government and develop strategies that promote effective leadership and community action in planning and implementing care, consistent with the culture of the community organization and its norms, standards and organizational structure: a single provider, separation between health and social care or separation of responsibilities at different government levels depending on the type of health care system.

Health professionals need to do the following.

1. Ensure they are adequately trained and up to date in both geriatrics and the palliative care of older people, including assessing and treating pain and other symptoms, communication skills and coordination of care.
2. Measure the outcomes of their routine care regularly, including for older people.
3. Ensure that older people with palliative care needs are regarded as individuals, that their right to make decisions about their health and social care is respected and that they receive the unbiased information they need without experiencing discrimination because of their age.
4. Ensure that their organizations work in coordination and collaboration with other statutory, private or voluntary organizations that may provide help or services for older people needing palliative care.
5. Participate in research, education and auditing that seek to improve palliative care.

Those funding research should do the following.

- 1.** Invest in programmes that develop and robustly determine the effectiveness and costeffectiveness of ways to improve palliative care for older people, including people with diseases other than cancer. These programmes should be sustained over a period of time so that new models of care and interventions can be developed and evaluated.
- 2.** Promote collaboration in comparing best practices in palliative care in various countries.
- 3.** Invest in creative research into the barriers to accessing palliative care, the origin and management of pain in diseases other than cancer and other symptoms older people have, their subjective experience of care, the mental and social needs of different cultural groups, the testing of advance care planning and meeting the needs of frail older people.
- 4.** Promote collaboration in research between palliative care and geriatric medicine, geriatric nursing and mental health services for older people and the inclusion of older people in all kinds of innovative research on physical interventions, including drug treatment.
- 5.** Disseminate the findings of research on palliative care for older people and constantly review the uptake.
- 6.** Monitor the proportion of funds in any disease or subject area that is directed towards palliative care research, especially that involving older people, and invest in redressing imbalances.
- 7.** Encourage innovative research (ideas that are most likely to make a difference in practice) to help people with serious chronic illnesses to live well and die well.
- 8.** Invest in methodological development in palliative care research among older people, especially among groups that are difficult to reach, including residents of nursing homes.
- 9.** Ensure that experts with relevant expertise assess research on palliative care among older people.