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Decisions at the end of life – Euthanasia – End-of-life care*

Decisiones al final de la vida – Eutanasia – Cuidado al final de la vida
Decisões de final de vida – Eutanásia – Cuidado de final de vida

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ABSTRACT: Considering that Euthanasia, decisions at the end of life, patient autonomy, assisted suicide, killing on request, end-of-life care and advance directives are subjects that attract enormous attention not only in Germany but also in every corner of the world, this paper intends to discuss legal, social, humanitarian and bioethical questions linked to these matters and present not only opinions of the public at large but also recommendations done about them by the German National Ethics Council.

KEYWORDS: Bioethics-the end of life. Euthanasia. Care.

RESUMEN: Como la eutanasia, las decisiones al final de la vida, la autonomía del paciente, el suicidio asistido, la muerte solicitada, el cuidado al final de la vida y directrices progresistas son tópicos que interesan mucho no solamente en Alemania pero en todos los cuadrantes del mundo, este artículo intenciona discutir cuestiones legales, sociales, humanitarias e bioéticas vinculadas a esos tópicos y presentar opiniones del público en general así bien recomendaciones acerca de ellos hechas por el Consejo de Ética Nacional Alemán

PALABRAS LLAVE: Bioética-final de la vida. Eutanasia. Cuidado.

RESUMO: Dado o grande interesse que a eutanásia, as decisões de final de vida, a autonomia dos pacientes, o suicídio assistido, a morte a pedido, o cuidado de final de vida e as diretrizes progressistas a esse respeito despertam uma enorme atenção não só na Alemanha como nos quatro cantos do mundo, este artigo pretende discutir questões legais, sociais, humanitárias e bioéticas vinculadas com esses tópicos e apresentar não só opiniões do público em geral como também as recomendações feitas a esse respeito pelo Conselho de Ética Nacional Alemão.

PALAVRAS-CHAVE: Bioética-final de vida. Eutanásia. Cuidado.

INTRODUCTION

Euthanasia, decisions at the end of life, patient autonomy and advance directives are subjects that attract enormous attention in Germany.

We have known for thousands of years that we must die. This knowledge has been a central aspect of all cultures through the ages and has been addressed by religion, ritual and ceremonies. In the past, death was mostly seen as fate. At least in peacetime, people generally died in the bosom of the family, and the dying were cared for by family members. This situation has changed dramatically. With the enormous advances in medicine today, more and more influence can be exerted over the course of an illness, life can be prolonged, or at all events the process of dying can be extended. Yet this does not necessarily result in a life in which due regard is had to human dignity. Although nearly all Germans would prefer to end their lives at home surrounded by close family and friends, the reality is very different. Some 90% of the population die in hospitals or nursing homes, often alone and in the absence of family members. Unfortunately there is not enough time for me to go into the many different reasons for this situation in this paper. But the effect has been to change our attitude to death and to unleash a vigorous debate on the permissibility and limits of euthanasia.

As far as the public is concerned, attention no doubt focuses mainly on those high-profile cases in which the treatment of incurable patients or those in a persistant vegetative stage is terminated. For instance, the fates of Terri Schiavo in the United States and Diane Pretty in the United Kingdom were the subject of the widespread media coverage. As a result, the helplessness of patients confronted with the ever increasing efficiency of medicine

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has become very conspicuous, and has surely also fuelled the debate on the scope and binding character of advance directives, as well as on the permissibility of euthanasia.

Unlike some other Western legislations, German law includes hardly any statutes governing the sphere of euthanasia and decisions at the end of life; virtually everything is based on case law. The German legal order includes an elaborate codified system of provisions on inheritance and property, but these do not of course fall within the present context. The decisions of the courts are inconsistent, and judgements in criminal cases sometimes contradict those in guardianship matters.

It is not only lawyers who have to cope with both theorical and practical ambiguities and anomalies; medical practitioners too face uncertainty. All empirical studies show that most doctors know little, if anything, about the permissibility of the various medical aspects of end-of-life care.

Apart from these uncertainties, however, opinions on the permissible limits of helping people to die vary greatly among all those professionally involved with these issues (as they do in society at large). It is not only a question of differing values but also of a diversity of approaches from one profession to another. A reliable normative framework is urgently needed.

LEGAL FRAMEWORK

Only the criminal law deals explicitly with euthanasia, and it stipulates only that killing on request is a criminal offence. This provision dates from 1871, when the criminal law was codified for the whole of newly unified Germany for the first time. At that time, suicide too ceased once and for all to be punishable. Accordingly, under German criminal law participatory acts are also not punishable. This applies in particular to assisted suicide. However, the courts repeatedly find against doctors and family members for failing to render assistance – which is a criminal offence according to the Penal Code, although this refers only to accidents – if they do not prevent a suicide although they could have done so.

For guidance in the regulation of other decisions at the end of life, we must therefore turn first to fundamental ethical and legal principles. The achievements of the European Enlightenment, the Christian heritage and the conceptions of the German idealist philosophers, as well as our experience of National Socialism and the catastrophic Second World War, all contributed to the creation of the German Constitution, which is known as the Basic Law.

Hence there is unanimous agreement that, in constitutional terms, acts and decisions must be assessed by the criteria of human dignity (Article 1 of the Basic Law), the right to free deployment of the personality (that is, to self-determination) (Article 2(1) of the Basic Law) and the right to life and bodily integrity (Article 2(2) of the Basic Law). The ethical discussion takes into account not only the protection of life and bodily integrity and the self-determination, but also, and in particular, the principle of solidarity and care. Whereas these fundamental principles are unquestioned, opinions differ on the relative weights to be assigned to them. Here we find the reasons why criminal and civil courts come to different conclusions and why there is no consensus among the churches, politicians, the organizations representing the medical profession, legal experts and other groups. Put differently, the principles just mentioned are so general that sufficiently concrete practical guidance cannot be derived from them.

Whereas some are concerned to uphold self-determination and respect for self-determination at all stages of the dying process, others place more emphasis on such aspects as the protection of life and solidarity. As in the debate as a whole, these differences result from the protagonists' differing images of man: while the former group believe more in the capacity for self-determination, the latter are particularly aware of the neediness of the old and the weak.

SPECIFIC SITUATIONS

It is clear from what I have said so far that there is little point in an abstract discussion of the issues, as the differences emerge only from specific cases of conflict.

First, a terminological point. The word *Euthanasie*, which is equivalent to "euthanasia", is not used in German. The usual German term, *Sterbehilfe*, literally means "help with dying". Partly in accordance with international usage, the courts, the scientific literature and the organizations representing the medical profession have defined a number of specific situations for normative purposes – namely, indirect euthanasia, passive euthanasia and active

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euthanasia (the German word in each case being *Sterbehilfe*, as explained above).

The first of these terms is especially misleading because it is meant to denote *not* acts intended to bring about death but measures to relieve suffering, even if death is thereby hastened in individual cases. Examples of such measures are pain relief with morphine and sedation to control anxiety. We should therefore speak instead of end-of-life care and therapies at the end of life.

"Passive euthanasia" relates to the termination or withdrawal of treatment. The term is problematical and confusing particularly for doctors and nurses, as the omission of further treatment may involve an active intervention, such as the turning off of a ventilator or the removal of a feeding tube. For this reason, the term "letting die" is preferred.

"Active euthanasia" has nothing to do with help, in the sense of helping someone to die, but denotes the bringing about of a painless death; legally, this amounts to killing on request or to manslaughter.

1. End-of-life care and therapies at the end of life

Therapies at the end of life and end-of-life care include not only pain relief and sedation but also all other forms of palliative medicine and hospice care. Here one would expect to find the principal fields of application of end-of-life care. In Germany as elsewhere, though, we are far from being able to guarantee adequate general and palliative care consistent with human dignity. We need better advanced training for medical practitioners, especially in the treatment of pain. Doctors still believe they may be liable to prosecution if they give dying patients such high doses of drugs to relieve pain or anxiety that death sometimes occurs a little earlier. Even if legal opinions differ on the status of these therapies at the end of life, and especially on where to draw the line between a legitimate act and prohibited homicide, everyone now agrees that the application of these therapies is demanded by considerations of human dignity and that it should not incur penal sanctions.

In addition, there is an urgent need for ancillary provisions in employment law. Family members are often prevented from caring for dying relatives by their contracts of employment. The law must provide for a period of unpaid leave to allow family members or close friends to care for a dying person without fear or losing their jobs. Such a system already exists in other countries, such as France.

Interestingly, while on the one hand the demand for self-determination is expressed ever more vociferously, on the other the public's commitment to the hospice movement and to care of the weak and the sick is constantly growing.

2. Letting die

Most people in Germany now agree that doctors and nurses must terminate or withdraw a treatment if the pacient so requests. After all, the continuation of a treatment too calls for the patient's consent, even if the terminal phase has not yet begun. In the case of a patient who is capable of expressing his wishes, the right to self-determination takes priority; from the legal point of view, continuation of the treatment against the patient's will would constitute the infliction of bodily harm. The medical profession and care institutions have difficulty with this precept, and sometimes invoke conscience-based decisions or contractual provisions governing the admission of patients. These problems must be addressed on the level of organization; at any rate, compulsory treatment is impermissible. This also implies that where appropriate a doctor must turn off a ventilator or remove a feeding tube. For many years nutrition and hydration were seen as an indispensable part of basic palliative care, which a patient could not refuse even in the exercise of self-determination. For some time now, however, a distinction has been made between the relief of subjective sensations – for example, the allaying of hunger and thirst – on the one hand, and an emphasis on life-sustaining medical measures on the other. Only the first case constitutes indispensable basic nurture that does not require justification.

Opinions differ on cases where people who are not capable of expressing their wishes are allowed to die, and these differences are reflected in the decisions of the courts. If an advance directive exists, it may be seen as a legally valid expression of the person's wishes. Even if the initial legal situation is unequivocal in accordance with settled law, there is considerable disagreement as to whether, and if so to what extent, patients can articulate their wishes in binding form in relation to a future time when they may no longer be capable of expressing them. Whereas other Western states have already adopted statu-

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tory provisions on this situation, in Germany we have so far had only court decisions in individual cases. We hope that a law will be passed before the end of the current parliamentary term.

Most legal experts consider than an advance directive is binding on doctors and nurses if it is precise, even if the terminal phase has not yet begun. Particularly thorny problems and difficulties are presented by dementia sufferers and patients in a persistent vegetative state. Advance directives are an instrument of self-determination whereby a patient wishes to ensure for the future that his wishes, which must be respected, remain the criterion of what is permissible when he is no longer capable of expressing them. An argument in favour of this position is that a mentally competent individual can himself take responsibility for his fate and must not be subjected to the control of another, however well-meaning; at most, a trusted person, such as a member of his family, should be able to decide for him in the capacity of an agent.

This conception of the law is opposed by many theologians, medical experts and ethicists. Their arguments, which are partly empirical and partly ethical, are based on the protection of life: patients should not be held to an expression of their wishes; in cases of doubt they would want to live; the ending of life is irrevocable and conflicts with the protection of life, which is the highest of all goods. Doctors should therefore decide in the presumed current interests of the patient and be allowed to depart from the provisions of an advance directive. Hence an advance directive can be deemed binding, if at all, only in the terminal phase. That is all the more reason for not regarding the patient's "presumed wishes" as a substantial criterion until this phase commences.

However, most agree that there should be no question of criminal of professional sanctions where, having regard to its prospects of success, the patient's suffering and his probable life expectancy, a medical treatment is no longer indicated and is therefore withheld, limited or withdraw. In cases of doubt, the principle that life takes priority is paramount.

The attitude of the public to this issue is interesting: the majority of respondents in representative surveys consider that advance directives should normally be binding on doctors, while a substancial majority believe that this should be the case even if the process of dying has not yet begun.

3. Suicide, suicide intervention and assisted suicide

On the approximately 12 000 suicides unfortunately recorded every year in Germany – in addition to those that go unrecorded and to many attempted suicides – most are attributable to mental disturbances, such as depression or schizophrenia. Other suicides and attempted suicides are due to situational despair. In by far the majority of cases, suicide attempts are in the nature of an appeal. It goes without saying that everything possible should be done to prevent such suicides or to save the lives of those concerned, and I shall therefore not discuss this point any further.

The situation is as a rule different where a mentally competent patient suffering from an incurable illness decides to commit suicide. This is described in the criminal-law literature as "rational suicide", in which the patient resolves on the basis of mature reflection that, on balance, he does not wish to continue living. Not even loving emotional support and comprehensive care will change the patient's mind in cases of doubt.

Opinions on the ethical permissibility or otherwise of seriously contemplated suicides have varied greatly from classical antiquity to the present day. The retreat from the imposition of penal sanctions in the criminal law has not been paralleled by a reduction in the moral opprobrium attaching to suicide. But there is no consensus on this point.

Two different ethical positions can be distinguished with regard to the suicide of a patient suffering from an incurable illness. According to the first, suicide must always be seen as a deliberate act of contradiction to life and hence as contrary to the conditions of self-determination. This conception can also be described in terms of theological categories. Suicide then appears – for all the human understanding that must be brought to bear in an individual case – as an impermissible attempt to pronounce a definitive judgement on the worth or worthlessness of the person's own life. Behind this view one can discern the ideas of the German philosopher Immanuel Kant, who held that self-immolation was an act of destruction of the moral law and a violation of the dignity of man.

According to the second position, suicide can perfectly well be ethically permissible. If self-determination can serve the pursuit of an individual's profoundly held convictions and personal conceptions of a correct and good

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life, provided that the rights and legitimate demands of others are not infringed, then it follows that personal notions of the right way to die, including suicide as the *ultima ratio*, must also be respected.

Whichever of these two positions one espouses, it seems inappropriate for a moral obligation to be imposed on family members or others close to the patient to intervene in the event of suicide. And if someone who is incurably ill has made a serious decision to take his own life, these persons should not be liable to prosecution for failing to render assistance. However, legal and medical experts disagree on whether this should also apply to doctors. Some would prefer this possibility to be confined to gravely suffering patients in the terminal phase of life. Others hold that doctors must respect the suicide's self-determination and refrain from intervening.

The ethics of participation in suicide, whether in the form of instigation or of assistance in the commission of the act, are also the subject of vigorous debate in Germany. Whereas instigation is almost universally seen as ethically repugnant, individual assistance of someone who is gravely ill by close family members is widely regarded as not morally objectionable. Divergent views are held on assistance by physicians. Doctors are not uncommonly called upon to assist someone who has resolved to take his own life in the preparation or commission of the act. They have access to drugs or can prescribe them, and drugs are often the only practicable method of committing suicide for a person who is seriously ill. Most medical practitioners, as well as the German Medical Association, consider physician-assisted suicide to be irreconcilable with the medical ethic and with a doctor's duty to heal. The arguments fall into two different groups. First, there is the risk of abuse; a patient's resistance to suicide might be weakened bacause death would be easier; and doctors could find themselves under pressure. Second, there are difficult issues of definition and demarcation: how is a doctor to determine whether the patient's decision to take his own life was arrived at without constraint and on his own responsibility? The risk of error here is felt to be too great.

Proponents of the opposite position also invoke the medical ethic. In their view, as a rule this admittedly enjoins prevention and cure, but subject to respect for the patient's self-determination. In the crisis situation of incurable illness, when desperate individuals are resolved to take their own lives, physician-assisted suicide too might be consistent with a doctor's duty to act in the best interests of the patient and would therefore be covered by the medical ethic. According to this conception, problems of definition and demarcation are less significant than with other end-of-life decisions, since those resolved to commit suicide are mentally competent and capable of expressing their wishes, as the doctor can determine for himself. Experience in other countries shows that, even where assisted suicide is legal, resistance to the taking of one's own life persists.

A third view is that doctors must decide on the basis of their personal conscience; each instance should be seen as an individual tragic case in which the doctor must make his own decision.

4. Voluntary euthanasia organizations

Assisted suicide facilitated by organizations such as those existing in Switzerland arouses universal misgivings. Whereas all members of the National Ethics Council, of which I am the Chair, agree that for-profit organization of suicide should be prohibited, if necessary by making it a criminal offence, opinions on other aspects differ. Some regard organized assisted suicide as permissible as long as physician-assisted suicide is not allowed, subject to requirements of transparency, counselling and state supervision. The patients concerned cannot simply be left to their own devices, nos can the responsibility be placed on the shoulders of overstressed family and friends.

That said, most members of the National Ethics Council, as well as the majority of the public at large, have fundamental objections to any form of organized assisted suicide, because its availability would confer 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 putting their intention into effect.

KILLING ON REQUEST

The situational here is in a sense paradoxical. Public opinion, most authorities on the criminal law and the decisions of the courts agree that killing on request constitutes homicide and that it should remain a criminal act. However, a vigorous debate is currently being waged

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among criminal-law scholars as to the distinguishing criteria that can justify the prohibition of killing on request on the one hand, and permitted assistance with suicide and permitted therapies at the end of life on the other. Experts also differ on whether, and if so by what form of legal construction, violation of the prohibition of killing can be justified or excused in extreme circumstances where a dying patient is suffering unbearably. Yet most in Germany ultimately agree that provision for exceptional situations expressly permitting the killing of the incurably ill at their request should not at present be introduced into the criminal law. This shared conclusion is in fact based on a diversity of arguments.

Anyone who already regards assisted suicide as unacceptable will a fortiori reject actual killing. However, even for those who do not rule out assisted suicide in every case, helping someone take his own life on his own responsibility is so different in category from killing another person that the taboo on killing must absolutely be retained. Another relevant factor here is the fear of abuse and of social pressure, exerted for instance by family members.

Others, while not denying the fundamental categorial difference between suicide and homicide, point out that the rejection of assisted suicide should not necessarily be made dependent, when all ethical aspects are taken into account, on this consideration. This is so particularly when an incurably ill person is no longer capable of killing himself by his own hand. Yet the advocates of this position reject the idea of statutory exceptions because these might weaken the taboo on killing.

A minority see all these distinctions as irrelevant, but reject any qualification of the prohibition. Their reasons are political, based on the German history of criminal euthanasia under the Nazi regime.

The conclusion that the present legal position should remain unaltered seems to be substantially shared by all parties – politicians, legal experts, representatives of the churches and the medical profession. The debate is thus very different from that in the Netherlands or Belgium. Public opinion as reflected in the results of representative surveys is therefore all the more interesting.

The right to self-determination is a much more dominant element of the debate than the political class realizes. Various surveys show that three quarters of respondents think that the seriously ill should have the right to enlist the aid of doctors for suicide or active euthanasia. This does not necessarily mean that they themselves would take advantage of this right; only a minority would contemplate that. However, acceptance of active euthanasia is reduced and in some cases reversed by the hope of alternatives such as palliative medicine and the hospice movement. It is here that the prospect of a consensus in society arises. After all, the more progress is made in palliative medicine and the more the care of the dying and the easing of the process of dying by family members or hospices is facilitated, the less will be the differences between those whose priority is autonomy and those whose paramount concern is with the care and protection of the weak.

Nationaler Ethikrat
Self-determination and care at the end of life

OPINION
RECOMMENDATIONS

Fields of action and terminology

The National Ethics Council considers the terms “active euthanasia”, “passive euthanasia” and “indirect euthanasia” to be open to misunderstanding and to be misleading. Decisions and acts at the end of life that have direct or indirect effects on the process of dying and the onset of death can be appropriately described and distinguished by use of the following terminology:

The term “end-of-life care” denotes measures for the nursing and care of individuals in whom the process of dying has already begun. “End-of-life care” includes, for example, bodily care, the allaying of feelings of hunger and thirst and the relief of nausea, anxiety and breathing

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difficulties. It also involves emotional and spiritual support for the dying patient and his family.

"Therapies at the end of life" comprises all medical measures – which thus include palliative care – adopted in the final phase of life with the aim of prolonging life or at least of relieving suffering. They include measures that may have the incidental effect of hastening the natural process of dying, whether on account of high doses of pain-killing drugs or of powerful sedation, without which grave symptoms cannot be controlled. The term "indirect euthanasia" previously used in this connection is inappropriate, because the relevant actions are intended neither directly nor indirectly to bring about the patient's death.

The term "letting die" should be used instead of "passive euthanasia" where a life-sustaining medical treatment is withheld, so that the death resulting from the course of the disease occurs earlier than might be anticipated with the treatment. The withholding may involve not initiating a life-prolonging measure in the first place, or alternatively not continuing a measure already begun or actively withdrawing it.

"Assisted suicide" denotes the situation where doctors or other persons procure a lethal drug for someone or otherwise assist him in the preparation or commission of suicide undertaken on his own responsibility.

"Killing on request" refers to acts whereby a person's death is actively brought about in response to a serious request by that person. Such acts may comprise, for example, the administering of a drug not indicated therapeutically or an overdose of indicated drugs.

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.

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 withdraw.
5. The preservation of life must take precedence in cases of doubt.

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

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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.

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 explicity 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.

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