

German Bundestag
(15th electoral term)

Study Commission

Ethics and Law in Modern Medicine

Interim report on living wills
(Printed Paper 15/3700)

Short version

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Berlin	December 2004

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What is the problem?

Living wills are a subject of debate. The ethical and legal assessment of living wills is a matter of controversy; the conditions for their validity are unclear; uncertainty reigns for many people who wish to make provision for the end of their lives. The Study Commission has discussed this subject in great depth and in its interim report (Bundestag printed paper 15/3700) set out detailed recommendations for the German Bundestag, calling for the creation of greater legal certainty, the fundamental recognition of living wills and also the clear determination of their limits.

What are living wills?

Living wills are declarations of wishes, in which individuals set down the ways in which they would wish to be medically treated or not treated if, for health reasons, they themselves were no longer able to give consent.

The fact that the legality of any medical procedure depends on the consent of the patient is indisputable. However, whether wishes expressed in advance can be equated in all cases with current wishes is questionable. A further matter for dispute is also the question of what scope a living will has or should have, i.e. in what situations of illness it becomes valid. Finally, the matter of what formal requirements a living will needs to satisfy in order to be valid is also the subject of debate.

All members of the Study Commission are clear that the interim report must not obscure the fact that living wills are only one means – and not the most important – of rendering more humane the conditions surrounding dying in our society. The decisive factor is improved support for the seriously ill and dying, with strengthening of palliative medicine and hospice facilities. The debate around living wills must always be seen in this context.

This short version of the report is intended to give Parliament and the public a rapid overview of the core recommendations made by the Study Commission and the considerations on which they are based.

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Binding nature of living wills

The right to make arrangements with regard to medical treatment is based in constitutional law. The wish not to be treated is also protected by basic law. Living wills are therefore also fundamentally binding.

It is an illusion, however, to believe that the implementation of living wills is always clear and unequivocal. Every declaration of wishes, every utterance and every text requires interpretation. This is particularly the case for statements relating to future developments that are difficult to predict and, moreover, circumstances in which the person concerned is no longer capable of taking a decision. And with an interpretation of this kind extreme care is required when the process results in irreversible decisions concerning life and death. Rigid determination of the binding nature of living wills by the legislator is therefore not permissible.

When implementing a living will, investigation is necessary in each case to determine whether the current medical situation corresponds to one of the situations described in the will, whether the treatment desired or refused in the living will is the same as the treatment currently indicated and whether there is any change in the individual's wishes. Since a number of ambiguities exist here that can lead to difficulties in reaching a decision, the possibility of its implementation may be limited or annulled in spite of the binding nature of the will in principle.

Scope of living wills

Living wills that provide for discontinuation or refusal of treatment, which would lead to death, should not be valid irrespective of the progress of the illness but only where the prognosis is poor, that is, in cases where the underlying disease is irreversible and to the best of medical knowledge would lead to death in spite of medical treatment. Basic care measures should not be capable of exclusion by living wills.

This limitation on the right to self-commitment is supported by a number of arguments. These include in particular:

- Provisions made in advance and current expressions of wishes cannot be treated in the same way. In the case of a current expression of wishes, the patient is able to deal with the concrete situation in which he finds himself and any options arising from this. In the event of inability to express one's wishes and in a living will, this is no longer possible. This is not a direct exercise of the right of self-

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determination but an arrangement made in advance that can only represent a framework for a situation that is difficult to predict.

- It is repeatedly found that individuals who are seriously ill often change their attitude to life and assess a life situation involving illness and limitation more positively than they would have done in advance when they were healthy.
- From the State's obligation to protect human life, the duty arises to avoid the development of a climate in which pressure can be exerted on elderly and seriously ill individuals to have their lives ended, in the event of loss of their ability to act and communicate, by means of a living will.
- Wishes relating to dying are not the result of an isolated individual decision process but are influenced by media and social trends.

Limiting living wills that relate to the discontinuation or withholding of life-support measures to illnesses that lead to death is also justified by the fact that death occurs in these cases as a result of the absence of further treatment for the illness, and takes its natural course. By contrast, in the event of discontinuation or refusal of life-support measures in a treatable disease, e.g. withdrawal of nutrition, death itself occurs primarily due to the discontinuation or withholding of treatment. According to the previously unanimous and proven view, this can only be legitimised, however, by the directly expressed wish of the patient, who must be aware in that situation of the consequences of his decision, and not by a wish expressed at another time and certainly not by an assumed wish.

The proven protective function of the principle of medical ethics, that "in case of doubt one should always decide in favour of life", should not be abandoned lightly. Otherwise the principle of protection of life and prohibition of killing by omission would be generally neutralised by living wills. This would also call into question the prohibition of active killing on demand. The Study Commission wishes to counter these consequences by limiting the scope of the living will.

Illnesses such as waking coma and dementia, which in themselves do not represent irreversible fatal underlying diseases unless additional severe incurable diseases develop, accordingly do not permit the withholding of life-support measures, even if this was expressed as a wish in a living will.

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Conditions for validity and promotion of validity

Living wills should only be valid if they exist in written form and are signed.

The import of decisions concerning life and death arising from the execution of a living will demands the highest possible degree of certainty as to whether a living will exists at all and, if so, what its contents are. The written form is both an effective and simple means of achieving this. Verbal declarations do not offer this certainty, and carry with them a great risk of misunderstanding, gaps in memory, misinterpretations, and lack of due reflection.

To avoid making the management of living wills excessively difficult for the author and user, the Study Commission is against the imposition of further requirements with respect to the validity of living wills over and above the written form. At the same time it recommends further measures to increase the validity of living wills in practice:

- An explanatory and advisory meeting before making the living will with qualified advisers, e.g. from the spheres of medicine, law or the hospice services. This meeting should be documented by means of an appended declaration.
- Updating of the living will at regular intervals (e.g. every two years).
- The clear articulation of any revocation of a living will, e.g. by means of a written note on the will or by destruction of the will. The written wishes expressed in the living will, however, may be revoked informally at any time.
- Carrying of an information card showing that a living will has been made, the date on which it was made and where it is lodged.
- Supplementation of a living will with a power of attorney or guardianship instruction, so that while setting down one's own wishes, the individual who is to implement these wishes at a later date is also named.

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Execution of living wills

It is not only legal regulation of their status and conditions for their validity that are the decisive aspects in the management of living wills. The way in which their implementation is handled is also crucial. Here the Study Commission recommends two instruments: a case conference to determine the patient's wishes and examination of this determination of wishes by a Court of Protection.

Rarely can a living will simply be executed as it stands. Every living will requires interpretation. This interpretation complies as closely as possible with the content intended by the author when the various perceptions and views of all those who are close to the patient or caring for him during his illness have been taken into account. This should take place within the framework of a joint discussion. The Study Commission therefore recommends legal regulation to ensure that, where the refusal or discontinuation of life support measures are concerned, the legal representative (guardian or attorney) should be advised by a case conference. The case conference should include the doctor providing treatment, the legal representative, a member of the care team and a relative. The deliberations of this case conference include the following:

- Establishment of the formal validity of the living will.
- Determination as to whether there is any evidence of an appreciable current change of mind. Changes of mind must be respected even if they cannot be said to be an explicit revocation of the previous declaration. The natural wishes of the patient currently expressed take precedence over the living will.
- Examination as to whether and to what extent the actual current medical situation matches one of the situations described in the living will.
- Examination as to how the wishes expressed in the living will can best be applied to the actual medically indicated treatment.

The joint discussion of all those involved, with a view to reaching a consensual outcome, offers the greatest guarantee that all views and information will be taken into account, that fixed assumptions and judgments regarding the person concerned can be overcome, with the exclusion of self-interest but also of routine medical practice. It is the best way of applying the wishes expressed in the living will to the actual current situation in conformity with the wishes and values of the patient. A case conference of this kind therefore does not represent a bureaucratic limitation of the right of self-determination but is necessary precisely for

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the sake of such self-determination. It takes account of the need for “narrative-based medicine”, which would make an important contribution to the improvement of our health system.

The purpose of the case conference is communicative determination of the patient’s wishes. In view of the weight of decisions concerning life or death, however, further precautions are necessary in procedural law to ensure that the decision of the legal representative actually corresponds to the patient’s wishes. The Study Commission therefore recommends regulations to ensure that the legal representative’s refusal of consent to a medically indicated life-support measure requires the approval of the Court of Protection.

The Court of Protection examines whether deliberation by the case conference has taken place, whether the decision of the attorney or guardian conforms to the wishes of the patient and whether the further objective conditions for validity of the decision are in place. Examination by the Court of Protection therefore serves to protect the patient from abuse.

Proposals for legislation

The Study Commission proposes the following legal formulation for the implementation of its central recommendations (Civil Code, volume 4, section 3, title 2):

§ 1901 b [Living will]

- (1) An individual who is capable of giving consent may set down in writing which medical procedures he or she wishes to accept or decline in the event of loss of his or her ability to give consent (living will). The ability to give consent exists if the person can assess the significance, scope and consequences of the declaration. The provision of basic care cannot be excluded by a living will.
- (2) The guardian must examine the living will. If there is no evidence that the author has had a change of mind or would have come to a different decision if the present circumstances had been known, and if the decision taken in the living will applies to the present situation, the guardian must execute the living will.
- (3) If the purpose of the living will is to withhold or discontinue a medically indicated or life-supporting procedure proposed by doctors, the guardian may execute the living will only if the underlying disease is

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irreversible and will lead to death, to the best of current medical knowledge, in spite of medical treatment.

- (4) If a person capable of giving consent has declared or expressed in some other way what medical procedures he or she wishes to accept or decline in the event of loss of capacity to give consent, the attorney shall take this declaration into account as an indication in determining the wishes of the protected person. A life-support procedure that is medically indicated or proposed by doctors may only be refused if the underlying disease is irreversible and, to the best of medical knowledge, will lead to death in spite of medical treatment.
- (5) In case of doubt in the execution of a living will or a verbal declaration, the wellbeing of the protected person and protection of his life takes priority.
- (6) Faced with the decision as in paragraph 3 and paragraph 4 sentence 2, the attorney must obtain advice from a case conference. The case conference should involve at least the doctor providing treatment, a representative of the person being cared for and, if available, a relative. Consultations should consider in particular the following questions:
 - Whether the living will is formally valid,
 - Whether there is any indication of an appreciable current change of mind,
 - Whether and to what extent the actual current medical situation conforms to one of the situations described in the will,
 - How the wishes expressed in the living will may be applied to the actual medically indicated treatment.

The consultation takes place in the form of a joint meeting with the guardian, the outcome of which must be documented.

- (7) The guardian's refusal to give consent to the initiation or continuation of a medical procedure in accordance with paragraph 3 and paragraph 4 sentence 2 is permissible only with the approval of the Court of Protection.
- (8) Paragraphs 1 to 7 apply analogously to the decision of the attorney. The power of attorney is valid only if it is given in writing and expressly includes the procedures mentioned in paragraph 1.

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In addition, § 1896 para. 1. BGB is to be modified: In paragraph 1 after sentence 1 the following sentence is to be inserted: "This applies even in cases where a living will exists."

Dissenting opinions

The recommendations described were agreed by a broad majority of the Study Commission. There were, however, some dissenting opinions directed against central recommendations of the interim report. This applies in particular to:

- The scope, with limitation to irreversible underlying disorders which, in spite of medical treatment, will lead to death, is rejected (Albers et al., Kauch et al.).
- Requirements for validity under which the written form is not regarded as sufficient as the only criterion, and also demonstration of the provision of medical information and updating of the will are recommended as preconditions for validity (Albers et al.).
- Examination by the Court of Protection, which should not take place in every case but only in the event of disagreement between the legal representative and the doctor (Kauch et al.).

One dissenting opinion rejects the legal regulation of living wills entirely, since they are an unsuitable means of ensuring death with human dignity (Beckmann).