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Interim report

Living wills

by the “Ethics and Law in modern medicine” Study Commission*

Excerpt

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6. Conclusions and recommendations

6.1 Legal status of living wills

The “Ethics and Law in modern medicine” Study Commission finds that the right to make provisions with regard to medical and nursing treatment is embodied in constitutional law. The wish not to be treated is also protected by basic law. This also applies in principle to the determination of measures to be taken or not to be taken in future in the event of incapacity to take decisions or to communicate one’s wishes. Provision for the event of incapacity to take decisions or communicate one’s wishes is possible by expressing one’s wishes concerning treatment one does or does not wish to receive in the form of a living will and/or by issuing a power of attorney or guardianship instruction.

The Study Commission takes the view that the wish expressed in a living will with regard to continuing further treatment in the event of incapacity to give consent is binding in principle, if the will was made voluntarily and in a state of mental competence. This means that doctors, guardians and attorneys are obliged to implement the patient’s wishes as expressed in the living will insofar as there is no concrete evidence of a change of mind and no statutory offence or other legally binding limitations on implementation of such wishes that preclude this. Provision for the event of incapacity to give consent, however, cannot apply irrespective of the stage of the disease process. Limitation of scope is possible under constitutional law[1] and ethically imperative (see section 6.2).

Establishment of the (theoretical) binding character of a living will is in most cases not sufficient to ensure implementation of the patient’s wishes. The decisive factor is the practical implementation of these wishes in the actual treatment situation and investigation as to whether there may have been a change of mind, since the current wishes of the patient take precedence over a declaration made in a living will.[2] In case of doubt, further treatment to protect life must always take precedence. The physician has a fundamental obligation to preserve life. If life-supporting measures are to be withdrawn, the wishes of the patient must be clear beyond doubt.

In each individual case, it must be established whether and to what extent

- the current actual medical situation concords with one of the situations described in the living will and
- the treatment desired or rejected in the living will corresponds to the currently indicated treatment.

Both in interpretation of the living will (what was the patient’s intention?) and also in determining the facts of the case (do the current circumstances match the situation described in the living will?), considerable difficulties can arise in reaching a decision. Therefore, even though the living will is binding in principle, its applicability in a concrete treatment situation may be limited or even abolished. In order to avoid such difficulties in decision-taking where possible and to ensure implementation of the patient’s wishes in the actual treatment situation as far as possible, the Study Commission also recommends below that certain requirements and criteria should be observed when preparing a living will (see section 6.4). In the view of the Study Commission, however, with the exception of written form these should not be an essential precondition to the fundamental binding nature of the wishes expressed in the living will but are merely to facilitate practical implementation of these wishes.

[1] See section 3.1
[2] See section 3.3.2.

In view of the lack of legal clarity, the uncertainties of doctors, guardians, attorneys and courts of protection in the application of living wills, the lack of clarity arising from the confusing number of regulations in civil and criminal law and, not least, the uncertainty of the public at large in deciding on whether or not to make a living will, legal regulation is now a necessity.

In the light of the situation described above, the "Ethics and Law in modern medicine" Study Commission of the German Bundestag issues the following recommendations.

6.2 Scope of living wills

The Study Commission recommends to the German Bundestag, when legislating on the validity of living wills that provide for discontinuation or withholding of treatment, leading to death, that it should limit validity to those cases in which the underlying disease is irreversible and will lead to death in spite of medical treatment, according to current medical knowledge. Basic care measures cannot be ruled out by living wills.

Explanation: The emphasis is on strengthening living wills. They are the expression of self-determination and enable individuals to deal at an early stage with the difficult and vital questions of the end of life. Too restrictive a regulation could assist the advocates of active euthanasia and enable them to gain support with strong images of excessive treatment and patients being treated against their will. The large number of living wills already in existence which include arrangements for situations prior to the terminal phase must also be taken into account. Living wills are generally made after mature reflection and often after personal experience of illness or prolonged suffering. These decisions should be respected.

Expansion beyond the group mentioned above would, in the view of the Study Commission, place an obligation on doctors to act in a way that would cause the death of patients not from their suffering or illness but from failure to support the vital functions of life.

Limitation of the scope of living wills therefore arises from the objective legal obligation of the State to protect life, which imposes on it the duty to avoid the creation of a climate in which pressure can be exerted on elderly and/or severely ill individuals to end their life voluntarily by means of a living will, and obliges it to minimise as far as possible the risk of abuse in the application of living wills. Particularly at times of shortage of resources, the risk that living wills that are unlimited in scope may be used as a means of cost reduction cannot be dismissed out of hand.

Limitation of the scope of living wills is also appropriate in view of the fact that one's wishes with regard to one's own death are not merely the product of an isolated individual decision process but are also subject to influence from social and media trends. Also, ideas expressed in living wills concerning one's own death may change in extreme situations.

Different procedures for living wills and current expressions of wishes are also justified since a living will is not a direct exercise of the right to self-determination but an arrangement made in advance for a situation that is very difficult to foresee. The Study Commission refers in this connection also to the ethical and legal problems associated with a living will in cases where, due to illness or injury, such a serious discontinuity in the personality of the individual concerned means that the binding nature of the living will should therefore be abolished.

For the above reasons, limitation of the scope of living wills does not represent a limitation of the current right to self-determination, but a well-founded limitation of the right to self-commitment.

Limitation of the scope of the living will to irreversibility and fatal outcome means that the authority to refrain from taking life-preserving measures in dementia and waking coma[3] without further life-threatening complications that will lead to the death of the patient, lies outside the possibilities of a living will. Dementia and waking coma as such are not irreversible fatal primary conditions in this sense. In case of doubt, the decision is always to be taken in favour of life.

Individuals in waking coma are neither dying nor brain-dead but chronically extremely sick, high-dependency patients who are dependent on care and assistance from those around them. The certainty of prognoses concerning the chances of recovery and rehabilitation in this area must be reassessed on the basis of recent findings from neurological and neuropsychological research. In particular, statements suggesting that an improvement in the symptoms (remission) is possible only within a matter of weeks or a year at the most may be constantly reiterated but are not tenable on the basis of the findings available. Clinical observations and studies on sensory stimulation, music therapy and the development of a close physical dialogue leads to the conclusion that early therapeutic measures are effective, and, in the majority of cases, allow at least successful yes-no communication to be achieved.[4] The prognostic differentiation between oxygen deficiency and injury as causes of waking coma, based on statistics from the beginning of the 90s from the USA and England in patients with no early rehabilitation[5], is also called into question by these findings. Overall, on the basis of the neurological and neuropsychological research findings and the successes of relational medicine, a seed change is occurring in the attitude to and understanding of patients in waking coma, offering a differentiated and life-affirming way of dealing with this group of patients.

6.2.1 Ethical justification

The self-determination expressed in a living will is binding to the maximum degree for the predicted situation. The following comments are not intended to call this into question, but to show that its binding nature is not exclusive or obligatory in every eventuality.

A difference exists between a will that anticipates the situation that has not been experienced existentially as such and a direct and current expression of wishes that relates directly to the situation and remains unchanged over a period. The living will is in this sense a substitute for the current and situation-related declaration of wishes where this is impossible. Such expressions of wishes can quite clearly not be equated with each other. To equate them would be to underestimate the changeability of the human being. This is true particularly of situations under extreme conditions in which the unforeseen invariably represents a large proportion of the picture. Only a view that takes account of the partial unpredictability of situations that can be only roughly typified does justice to the actual human being and does not transform him into an abstract entity. It is anthropologically inappropriate to confront the actual human being

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[3] The term “waking coma” is used here and in the following paragraphs because the term “persistent vegetative state” is questionable according to recent medical and neurobiological research. It is also discriminatory, because it is associated with a negative prognosis and assessment. The term is based on the view that the cerebral cortex is inactive, which is also reflected in the term “partial brain death”, and that there has been a separation between the cerebral cortex and the brain stem. On the contrary, modern imaging techniques demonstrate islands of cortical activity in the cerebral cortex of waking coma patients as a correlate for “recognising faces”, “hearing familiar voices”, “feeling pain” and “speaking words”. It is therefore assumed that in these patients the interaction of these zones of activity is interrupted, so that those affected can show no behavioural responses from which consciousness can be deduced.

[4] Cf., for example, Dolce/Sazbon (2002); Gustorff/Hannich (2000); Hannich (1993); Coma Recovery Association (1996); Zieger (2004).

[5] Cf. Multi-Society Task Force on PVS (1994a), Multi-Society Task Force on PVS (1994b).

with an ideal of self-determination that does not meet him where he is but attempts to place him where he – ideally – should be.

A further decisive factor is that the individual himself is not in a position at the time of the decision to interpret the previous expression of his wishes. Every text that is applied in concrete situations, however, requires interpretation. If this cannot authentically be given by the author, possibilities of interpretation exist that may depend on whether the situation in which treatment is to be declined has been precisely described and whether account has been taken of all means that are or will be available in this situation.

The living will is different from a testament in that a testament is not interpreted until after the death of the signatory. This situation of finality and immutability is different from the situation of the living person who is unable to comment on his own case and his situation. Even in dying, life is characterised by changeability. Here again the wishes of the living person who cannot interpret them himself require interpretation by a third party. It is the appropriateness of this interpretation that is in question. In order to guarantee equity of treatment, objective regulations are required.

An advance declaration of wishes stands in the situation in which it was prepared. Nor can this situation simply be considered in the abstract isolation of self-determination. Because of the involvement of the human being in his family and social environment, it is affected by ideas that are often based not only on his expectations for himself but also on expectations that others have for him or for themselves. This does not abolish the validity of self-determination, but means that it has to be handled with caution.

The living will relates to a situation in which the individual making the will is no longer the currently active person; instead, others are acting (or withholding action) on his behalf. These active persons enter the context of action with their own self-determination and ethos. All persons acting have their own responsibilities. To be confronted with a responsibility imposed from outside by a living will can lead to a conflict of obligations. This applies in particular to doctors and nurses and the options arising for them from their professional ethos and available to them in normal situations. To deviate from these in extreme situations such as the process of dying may, in the event of omission, not have the same weight as an active intervention. However, the circumstances in which they are acting can only be correctly interpreted with ethical relevance when the intention of the individuals currently acting is taken into account.

The living will would be understood very much as a device if it were seen primarily as a way of relieving individuals of difficult decisions. It should be an aid to these decisions but should not replace them or allow an appearance of legal security to replace responsible action. This is not to overlook the fact that legal security is a great good and that the situations in question must therefore not be seen totally subjectively. Objective criteria are necessary.

The idea of giving living wills a more or less binding nature, depending on the interval between their date of preparation and the situation itself, shows that interpretation criteria are needed. These criteria must operate on an objective basis and create objective methods for the problems of an individual case that cannot be dealt with objectively. The yardstick for these criteria is their adequacy (also known in the ethical tradition as fairness or equity, from the Latin "aequitas"), i.e. the possibility of being able to group as many problem cases as possible over a common denominator.

Finally, the sociomoral consequences of an illimitable living will made in order to refuse treatment must be seriously considered. Too little account is taken of these consequences in isolated legal logic. The Study Commission, in accordance with its instruction ("Ethics and Law"), wishes not merely to consider law purely in its intrinsic coherence but also to take account of the proven fact, which can readily be proven again at any time, that movements in

law also lead to movements in morality. Though the law cannot do away with the ethics that precede it and surround it in the form of life decisions, the law can influence spontaneous morality, i.e. ideas about what is “allowed” and “not allowed”, “permitted” or “forbidden”. Here politics has a responsibility with new legal regulations to determine their possible consequences. In this process, it is necessary to identify the possible consequences of misuse which could under some circumstances be prevented by means of appropriate protective mechanisms. The possibility, for example, that internal and external pressure to make the self-determined decisions for a living will may be brought to bear must be prevented, in view of increasing care requirements in sickness and old age as well as the growing inability to take one’s own decisions in such situations. The rationalisation of decisions concerning serious illness and situations at the end of life is an ambivalent development. This development should not only be promoted, but should also be steered along appropriate humane lines.

In addition to the sociomoral effect on general judgements and individual attitudes, it must also be borne in mind that in times of shortage of resources and limitation of distribution, the living will could be used as an instrument. It is possible that it could create an interpretation horizon that, insofar as the living will were allowed to be valid without limitation, would make this an obligation to withhold treatment that could be invoked by third parties and could therefore impose an ambivalent direction on the legislation. The embedding of judicial decisions on living wills in the trend towards shortage of resources is too obvious for this to be overlooked as a possible or even probable consequence. If, via the streamlined inbuilt plausibility of self-determination, economic shortage can be built up as a moral pressure, in the long term the individual will become secondary to the standard pattern and expected type.

The final question with regard to sociomoral effects also relates to the values that can be guaranteed by the social and legal institutions of the State. If these values are upheld only through the abstract ideal of individual freedom, loss of concrete freedom will be an inevitable by-product.

The value system also includes the “life” value for each human being not as the ultimate but as a fundamental good. A loss of value in the consciousness of human beings that is also reflected by social and legal standards, can lead to a downward trend. This downward trend can be intensified if the “life” value is also a matter for discussion – some feel for disposal – in other questions surrounding the beginning and end of life. An erosion of this kind is certainly intended by no-one, but should therefore be borne in mind carefully as a possible outcome, to which any unlimited binding nature of living wills could contribute.

People have images in their minds of what their lives will be like in situations of great stress and in the period preceding death. These images are not purely individual but also follow social and media trends in presentation. These may sometimes paint too idealised a picture of the options for living under great stress; but it has now become more usual to place great emphasis on the stress – in spite of palliative medicine and the hospice movement as objective alternatives offered. This places people under socially and legally promoted pressure to plan their lives and bring them under control. One should be responsible for one’s own “dignity” (understood here as a life with low stress and good reputation). This can lead to the misconception that human beings are able to overcome their mortal nature with regard to suffering and death. This may be true in individual cases insofar as situations of suffering can be shortened and stress can be reduced. But it is not true overall. The ideal death may generally remain just as much wishful thinking as the ideal birth. It is therefore desirable not to depend on the idea that life and death are totally subject to planning and control but also not to take a completely passive attitude. This insight can also be expressed in living wills and particularly in declarations of the wish not to receive treatment. Clearly this does not apply in all cases. The gap between responsibility for a possible future and the realisation that this cannot be planned comprehensively constitutes the problem of living wills and requires these to be handled in such a way as to establish a suitable relationship between the subjective desire and the objective circumstances.

6.3 Conditions for validity

The "Ethics and Law in modern medicine" Study Commission recommends that the German Bundestag should legislate that a living will must be set down in writing and signed. It should also be dated.

Explanation: Making the written form a precondition for validity should facilitate clarification of whether or not a living will exists at all and what the patient has said. In the case of verbal declarations, clarification of these questions by the doctor and guardians/attorneys would in some circumstances require comprehensive enquiries beyond the circle of those individuals involved in the treatment situation. Verbal declarations also involve a great risk of misunderstanding, gaps in memory, misinterpretations and excessive haste. Often, the seriousness of such declarations can be dubious. A verbal declaration can easily be made imprudently and on a whim. Since the living will involves particularly far-reaching and frequently irreversible decisions concerning life and death, the person making this will should be subject to particular protection from excessive haste, misinterpretation and abuse. The written form is the least complicated formal requirement.

Otherwise there would be an inconsistency of values with regard to other protective formal requirements in civil law. In particular, the written form is required for authority to give consent to a life-threatening medical intervention in accordance with § 1904 para. 2 BGB (Civil Code). Even for buying land authentication by a notary is required and a will must be made in writing. If, for the safety of those concerned, special formal requirements are laid down for authority to give consent to medical procedures and the disposal of material assets, this must apply even more for decisions concerning life.

This does not in any way mean that unwritten expressions of a patient's wishes are to be ignored, but must be regarded as an indication in determining his or her expressed or assumed wishes.[6]

6.4 Additional recommendations for the making of living wills

For all requirements relating to living wills that go beyond the minimum requirement of civil law, the "Ethics and Law in modern medicine" Study Commission recommends that the German Bundestag authorise the German government to circulate in a suitable way, in collaboration with the individual states, the following list of criteria as a guide to the preparation, updating, lodging and registration of living wills as a recommendation to all citizens. A possible vehicle would be Federal government and Federal Office for Health Education information brochures.

Explanation: For patients, it should be clear that these criteria facilitate implementation and therefore that the practical efficacy of their living will can be increased if these quality criteria are observed. However, it should also be emphasised that living wills must always be subjected to examination for applicability in any specific case and, because of the limited predictability of any situation in which a decision must be taken and the concrete medical options that then arise, there will often be difficulties of interpretation and problems in determin-

[6] Cf. section 3.3.2.

ing the facts. For this reason, it is often only possible to implement this by inference in accordance with the spirit of the will. By observing the recommended criteria, however, this examination of applicability and implementation will be considerably improved and the risk of misinterpretation minimised.

6.4.1 Provision of information and advice

The living will should preferably be drawn up after a meeting with a qualified person for the provision of information and advice. Qualified advisers from the spheres of medicine, law, psychology, nursing, hospice care and religion are suitable for this role. If such a consultation for the provision of information and advice has taken place, this should preferably be recorded in the form of an attached declaration.

Explanation: In view of the weight of the decisions taken in the living will and also to the complexity of the medical circumstances that can play a role at the end of life, consultation for the provision of information and advice, if possible with a specially qualified doctor but also with qualified advisers from other professional groups, such as lawyers, psychologists, nurses and theologists, should take place. This consultation offers the opportunity for thorough consideration of one's own wishes, the circumstances of the decision that may need to be taken and the consequences. In this way, the communication element of the doctor-patient relationship, which is lost or drastically reduced in the event of incapacity to express one's wishes, can at least have its place when the living will is drawn up.

If a qualified declaration is recorded, this is also an indication for the person later implementing the living will of its seriousness and the fact that the individual was capable of giving consent when it was made. If the author of the living will particularly values confirmation of his capacity to give consent, in order to give the living will a higher degree of validity, the consultation should be with a qualified doctor or psychologist, as only these professional groups can effectively confirm capacity to give consent. The offer of the qualified consultation must, however, remain voluntary not only because no-one should be forced to obtain information but also because this would otherwise scarcely be enforceable.

6.4.2 Updating

It is recommended that the living will should be confirmed by a new signature at regular intervals (e.g. every two years). A new signature and revision or amendment of the text is desirable if there is a change in the personal circumstances.

Explanation: In practice it is repeatedly found that the recent date of a living will is decisive for its practical validity and facilitates its implementation. Living wills that were drawn up long before the situation in which they are used are still basically valid but in this situation there is more reason to question whether the patient's wishes may have changed in the meantime.

6.4.3 Revocation

There are various ways of revoking a living will. This can either be done by means of a dated and signed written note on the living will or may be made clear by destroying

the living will itself. Informal revocation of the written wishes expressed in the living will, however, is possible at any time. Any change of mind on the part of the patient must be taken into account.

Explanation: In the event of revocation the living will may be destroyed, though deletion with an appropriate note of revocation is clearer. Destroying the living will in the event of revocation is not sufficient if third parties know of the will but have received no clear notice of its revocation. A living will that is remembered but cannot be found has a different effect in determining the wishes of the patient from that of a clearly revoked living will. It is therefore advisable in any case to inform the third parties who are aware of the existence of a living will in the event of its revocation.

It is not always possible for the patient expressly to state his change of mind. Determination of any change of mind that has not been recorded in a formal revocation is the purpose of verification of use in the actual treatment situation. However, strict requirements must apply to investigation of change of mind, so that this investigation cannot become the port of entry for third party decisions by the doctor, guardian or attorneys.

6.4.4 Lodging the living will

The patient should carry a card showing that he has made a living will and also the date of the will and where this is lodged. The various methods of lodging and central registration, for example in the register of attorneys of the Bundesnotarkammer (German Association of Notaries) or in the Federal Central Register of the German Hospice Foundation, are to be shown.

Explanation: Making a living will is no guarantee that the doctor treating the patient will know of this in the event of incapacity to take a decision or express one's wishes. The various models discussed, such as a central registration office or lodging of the will with the health insurance company would involve a considerable administrative burden. Carrying a card that indicates the existence of a living will, where it is lodged and possibly the name of a person with power of attorney, however, is a simple and effective means of providing notification of a living will. It also obviates the need for a legal regulation on the various possible methods of lodging and central registration. However, even when carrying a card the individual concerned should if possible always inform his associated that he has made a living will.

6.5 Implementing the living will

The "Ethics and Law in modern medicine" Study Commission recommends to the German Bundestag that it should ensure by means of a legal regulation that the guardian/attorney should be advised by a case conference in the event of refusal to start or continue a medically indicated life-preserving procedure. The case conference should involve the doctor concerned, the legal representative, a member of the care team and a relative. The conference should take the form of a joint discussion and be documented in the patient's records. In addition, the Study Commission assumes that the case conference will regularly be consulted concerning the interpretation of a living will.

Explanation: Implementation of the provision concerning rejection of life-supporting procedures in a living will should be based on a consultative dialogue model of decision-finding with a view to consensus. It requires the patient's legal representative together with the doctor concerned, a member of the care team and a relative to hold a conference and seek to reach a unanimous solution.

Points to be discussed by this case conference include

- establishment of the formal validity of the living will
- establishment as to whether there is any indication of appreciable change of mind at present
- examination as to whether and to what extent the actual current medical situation matches one of the situations described in the living will
- examination of the way in which the wishes expressed in the living will can be applied to the actual current medically indicated treatment.

The findings and investigations of the case conference are a prerequisite for the patient's legal representative to be able to declare the necessary consent to rejection of the introduction or continuation of the particular medical treatment procedure. If the attorney or guardian decides alone, the risk of incorrect assessments and misinterpretation of the living will is greater. Abuse based on self-interest is also more easily possible. Though It may be assumed in many cases that the attorney has a particularly close relationship with the patient and is aware of the patient's personal circumstances and values, this is not always the case; nor is it a prerequisite for granting the power of attorney. For this reason, involvement of the group of individuals named above who are dealing directly with the person concerned and know him is desirable in any consultation on the application of a living will.

Insofar as the attorney or guardian is not a relative of the patient, the immediate relatives are normally in the best position to contribute to clarification of the patient's wishes. A relative is therefore also to take part in the conference on application of the living will.

A precise definition of who must be heard and who not is possible only in the actual individual case and cannot be regulated in an abstract and general fashion by the legislator. Any such regulation would not be sufficiently flexible to satisfy the different requirements of each individual case. If the widest circle of friends and relatives were specified to avoid excluding anyone who might hold information, the group would be unmanageable and consultation difficult, without being able to achieve 100% certainty. In many cases individuals would then be involved who would actually not be able to contribute to a clarification of the patient's wishes and would at the same time make consensus more difficult to reach. However, if the regulation specified that only a small number of people were to be involved, important information from other individuals would not be taken into account.

The recommended regulation therefore provides for the obligatory attendance at the conference of the most important people (legal representative, doctor, member of the care team, relatives), but also the involvement of other individuals as necessary. This means that, where there is reason to suppose that further individuals may be able to contribute towards reaching the decision, these should also be involved.

A conference of this kind concerning the application of a living will does not represent a bureaucratic limitation of the right of self-determination but is necessary precisely to ensure self-determination.

The work of the case conference may consist of the simple determination that a living will is directly applicable to the actual situation without requiring further interpretation or, in other cases, assessment of how the wishes of the patient expressed in the living will can best be applied to the current actual situation. Moreover, in cases where living wills are incomplete,

not applicable to the situation or missing, the case conference may jointly determine what the presumed wishes of the patient are.

The joint conference of all those concerned in the task of reaching a consensual outcome offers the greatest guarantee that account will be taken of all views and information, will overcome fixed assumptions, judgements and prejudice relating to the person concerned, self-interest but also medical routine and therefore can find the best way of applying the wishes expressed in the living will to the current actual situation in the spirit of the wishes and values of the patient.

6.6 Involvement of the Court of Protection

The "Ethics and Law in modern medicine" Study Commission recommends to the German Bundestag that it should rule that the refusal by the guardian or attorney to consent to medically indicated life-supporting procedures requires the approval of the Court of Protection. The Court of Protection will examine whether consultation has taken place in the form of the case conference and whether the decision of the guardian or attorney complies with the patient's wishes and that the further objective conditions for validity of the decision are in place. Moreover, the Study Commission recommends to the German Bundestag that it should introduce a regulation that makes it clear that a guardian is to be appointed in accordance with § 1896 para. 1 BGB if expressed wishes are to be implemented that involve the refusal of medically indicated life-supporting procedures.

Explanation: In view of the consequences for the patient, refusal of consent to the introduction or continuation of medically indicated life-supporting procedures should be subject to approval by the Court of Protection. The conflict model, as proposed by the Federal Supreme Court[7] or the private decision model, according to which approval by the Court of Protection would be required only in cases of conflict between the guardian/attorney and the doctor, does not take into account the fact that the patient's representative and the doctor are presented with the possibility of controlling whether or not the Court of Protection is consulted by means of apparent disagreement and apparent agreement. However, the decision as to whether or not interventions in basic rights can be examined cannot be left to agreement between private individuals. In any case, a solution of this kind would contradict the basic rules and values of legislation governing guardianship law and the "procedural rationality of reservations concerning approval under guardianship law"[8], under which even termination of a renting agreement and, even more so, consent for a life-threatening medical treatment (§ 1904 BGB) requires the approval of the court. The much more serious consequences of a decision to withhold or withdraw medically indicated life-supporting procedures in particular requires the approval of the Court of Protection. A function of approval by the Court of Protection under guardianship law is also to relieve the guardian and the doctor from the sole responsibility and burden of the decision[9], which in the context of the risk of criminal prosecution is of even greater significance that mere decisions under civil law to be taken by the guardian. A flood of decisions or overloading of the courts is not to be expected, in view of the restriction to cases in which treatment is medically indicated, but is not to be given according to the wishes of the guardian/attorney, as previous practice shows, under which even cases where there is consensus have been submitted. If life-supporting procedures are to be terminated or withheld, this should always be monitored, even if no living will exists.

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[7] BGH (Bundesgerichtshof, Federal Supreme Court) (2003).
[8] Saliger (2004), 237 ff., 243.
[9] BGH (Bundesgerichtshof, Federal Supreme Court) (2003), 1593.

Recommendations 6.3 (written form) and 6.5 (obligatory case conference) should be legally regulated in guardianship law, since if the patient is incapable of taking a decision the conditions for guardianship are basically in place (§ 1896 para. 1 BGB). The equal treatment to date of decisions by guardians and attorneys (§ 1904 para. 1 and 2 BGB) should be incorporated accordingly.

In the guardianship law amendment act dated 25 June 1998[10] it was made clear in § 1904 para. 2 BGB that an attorney can give consent to a medical treatment.[11] The intention of the legislator was to strengthen the power of attorney and reduce the burden on the courts.[12]

In addition, protection of the individuals or patients concerned must be improved. Therefore, in questions of consent for a diagnostic investigation, curative treatment or a medical procedure, the legislator has made the attorney equal to the guardian and specified that the approval of the Court of Protection must be obtained. Involvement of the court as a neutral agency ensures a high degree of objectivity and rationality in this difficult decision. Without the control of the court, the patient is not to be subjected to a medical procedure that could result in his death or lasting injury, even where the attorney is expressly named. Like the guardian, the attorney is thereby relieved of the burden of final responsibility for the decision and its possible consequences.

Protection of the individual or patient concerned by the approval of the Court of Protection is even more appropriate in questions involving consent to the withholding or withdrawal of treatment that will lead to death. This already follows from the right to life enshrined in Article 2, paragraph 2 sentence 1 of the Basic Law.[13]

6.7 Proposed legislation for implementation of the recommendations

Bürgerliches Gesetzbuch (Civil Code)
Book Four. Family Law. Section 3 heading 2 Legal guardianship

§ 1901 b [Living will]

1) Individuals with the capacity to give consent may determine in writing which medical procedures they desire or reject in the event of loss of their capacity to give consent (living will). Capacity to give consent exists when the individual can judge the significance, scope and purport of the declaration. Basic care procedures cannot be ruled out by a living will.

2) The guardian has to examine the living will. If there is no reason to believe that the protected person has changed his mind or, if he knew of the present circumstances, would have reached a different decision and if the decision taken in the living will relates to the current situation, the guardian has to implement the living will.

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[10] Act amending guardianship law and further regulations (Betreuungsrechtsänderungsgesetz BtÄndG) dated 25 June 1998 (BGBl. I no. 39, 1580).
[11] The guardianship law amendment act (Betreuungsrechtsänderungsgesetz) came into force on 1 January 1999.
[12] German Bundestag (1997).
[13] Zum Pro und Contra der vormundschaftsgerichtlichen Genehmigung (The pros and cons of approval by the Court of Protection): Eberbach (2000), 268.

3) If the purpose of the living will is to refuse or withdraw a life-supporting procedure that is medically indicated or proposed by a doctor, the guardian may only implement the living will if the underlying disease is irreversible and, in spite of medical treatment would, according to the best medical knowledge, lead to death.

4) If an individual capable of giving consent has stated verbally or expressed in any other way which medical procedures he would desire or refuse in the event of loss of the capacity to give consent, the guardian must take this declaration as an indication in determining the wishes of the protected person. A life-supporting procedure that is medically indicated or proposed by the doctor may only be refused if the underlying disease is irreversible and in spite of medical treatment would, according to the best medical knowledge, lead to death.

5) In case of doubt in the implementation of a living will or of a verbal declaration, the well-being of the patient and protection of his life takes precedence.

6) Faced with a decision as in paragraph 3 and paragraph 4 sentence 2, the guardian must obtain the view of a case conference. The case conference must involve at least the doctor providing treatment, a representative of the nursing staff and, if available, a relative. The deliberations of the case conference must deal in particular with 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 matches one of the situations described in the living will
   - how the wishes expressed in the living will can be applied to the actual medically indicated treatment.

   The discussion takes place in the form of a joint conference with the guardian, the findings of which are to be recorded.

7) Refusal of the consent of the guardian to the introduction or continuation of a medical procedure as in 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 a decision by the attorney. The power of attorney is valid only if it has been granted in writing and expressly incorporates the procedures mentioned in paragraph 1.

§ 1896 para. 1 BGB is amended as follows:

In paragraph 1 after sentence 1 the following sentence is to be inserted:
"This also applies if a living will exists.".

6.8 Combination with general power of attorney or guardianship

The "Ethics and Law in modern medicine" Study Commission recommends those who have prepared or intend to prepare a living will to supplement this with a power of attorney or guardianship instruction.

Explanation: An individual preparing a power of attorney is thereby providing for decisions to be made in future situations in which he himself can no longer make the decision. In addition

to these substantive provisions for future decisions it is desirable at the same time to designate the person who is to act as representative in implementing these wishes. By granting a general power of attorney the patient himself is able to authorise an individual whom he trusts to look after his interests. If the attorney has a particularly close relationship with the patient and is informed of the patient's ideas, values and wishes, he is especially well qualified to undertake representation of the patient. A living will should therefore, if possible, be combined with a power of attorney or guardianship instruction.

6.9 Prohibition of link

The "Ethics and Law in modern medicine" Study Commission recommends to the German Bundestag that it conduct a legal examination as to whether and if necessary how a link between services and preparation of a living will should be legally prohibited.

Explanation: Making a living will is a voluntary precautionary measure. No-one should – directly or indirectly – be obliged to do this. Therefore it appears questionable if, for example, the intrinsically stressful situation for elderly or sick people of going into a residential home or hospital is misused to require them to make a living will. To this extent, the question of whether such a link should be legally prohibited should be examined.

6.10 Living will and organ donation

The "Ethics and Law in modern medicine" Study Commission takes the view that when providing information on the conditions and possible content of a living will and in publishing recommendations on this matter, the completion of a supplementary declaration on organ donation should also routinely be recommended. It should be explained that in a case where willingness to donate organs is expressed, the living will must state which declaration should take precedence if, in the event of death, organ donation is a medical possibility and whether, in the event of death, the medical procedures necessary to make organ donation possible will be agreed.[14]

A solution of the conflict between willingness to donate organs and the wish to reject treatment (see section 3.5) is possible neither by silence nor by interpretation of declarations, but only if it is stated in the living will which declaration is to take precedence in the event of a possible post-mortem organ donation – the declaration concerning willingness to donate organs including the intensive medical procedures required to make the donation possible or the limitation or rejection of such procedures as shown in the living will.

A recommendation to the effect that it should be established that the living will takes precedence in the case of doubt, as is sometimes proposed, is rejected by the Study Commission

[14] The Study Commission also refers to the formulation proposed in the notes on "Christian living wills". This reads: "Basically I am willing to donate my organs and tissues. I am aware that organs can only be taken after determination of brain death if the circulation is maintained. I therefore give my exceptional permission, in the event that it is medically possible for me to donate organs, for intensive medical procedures to determine brain death to be carried out in the short term (comprising hours to a maximum of a few days) and for the subsequent removal of the organs in accordance with the guidelines of the German Medical Council.", Kirchenamt/Bischofskonferenz (Ecclesiastical Office/ Bishops' Conference) (^{2}2003), 23.

in view of the importance of the legal values competing here. The recommendation that, where both a living will and also a declaration of willingness to donate organs is intended a prior medical consultation is particularly recommended, is helpful and to be supported. A recommendation of this kind, however, can easily give the impression that agreement to organ donation is the exception and the living will the normal declaration of those who are concerned about dying. This is in opposition to the socially and politically recognised aim to arrange for as many people as possible to make a declaration regarding organ donation (refusal to donate or agreement to donate or agreement limited to donation of particular organs). In view of the possible serious consequences, the public should be made aware of the connection between willingness to donate organs and living wills. This should also be included in the information provided according to § 2 TPG (Transplantation Act). The information that needs to be provided is that making an organ donation after death means that, in the event of death, all intensive care procedures necessary to maintain the circulatory system must be followed to allow the organ donation to take place. It should also be mentioned that where a living will both rejects treatment and also declares willingness to donate organs, it is essential for the living will to establish which measures should take precedence if there is the medical possibility of an organ donation. Clear reference should be made to this problem in the design of an organ donor card[15].

6.11 Final remarks

The "Ethics and Law in modern medicine" Study Commission assumes that the legal institution of the living will deals with only one aspect of issues concerning the dying in our society, and must be incorporated into a more comprehensive concept of care of the dying.

Explanation: Regulation of living wills is no more important than other aspects of dealing with the end of life. Attention to this subject was a priority because uncertainty has arisen in particular in this area. However, in order to allow a dignified death for all individuals an expansion of palliative medicine and greater promotion of the work of hospices are necessary.

[15] Bundesministerium für Gesundheit (Federal Ministry of Health) (1998).