



Patienten helfen

The New Federal Act on Living Wills in Austria

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On 1 June 2006, a new federal act entered into force (Federal Act on Living Wills¹, PatVG). For the first time, this Federal Act regulates (for the most part) the requirements for establishing a living will as well as the consequences and possible contents thereof in a legally clear and transparent manner.

Introduction

Historical developments have shown that there is a trend away from external control toward the right to self-determination. Decades ago, the prevailing view was that, as an expert, the physician alone had the specialised knowledge necessary to decide on a patient's welfare. The legitimisation for the treatment was therefore derived from the physician's superior specialised knowledge; specialised knowledge that is not available to the patient. It was therefore only logical not to involve the patient and not even to allow him or her to decide whether or not medical treatment was to be performed.

The legal situation and, above all, social opinion has undergone a fundamental change. Even in medical circles, it is now largely undisputed that the right to self-determination should be granted and that the *voluntas* (the patient's will) is more important than the *salus* (the patient's welfare). Indeed, the term *salus*, which continues to play an important role in certain situations, should be seen from the individual point of view of the patient

¹ Federal Act on Living Wills [Patientenverfügungs-Gesetz] (Federal Law Gazette. I No. 55/2006)

Impressum

Es ist enorm wichtig, permanent von den Patienten zu lernen. Im Letter PATIENTEN HELFEN stellt NÖ Patienten- und Pflegeanwalt Dr. Gerald Bachinger wichtige Erfahrungen von mit Patienten für Patienten und ihre Helfer vor. Dieser Letter ist ein Beitrag der NÖ Patienten- und Pflegeanwaltschaft, um vermeidbaren Problemen im Gesundheitswesen vorzubeugen. Er erscheint unregelmäßig, in der >NÖ Edition Patientenrechte<, seit Juli 2001 auf www.patientenanwalt.com zum Download.

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rather than from that of the physician or "normal person". This also means that refusals of medically indicated action (e.g., the refusal of a blood transfusion by a Jehovah's Witness who is of sound mind and judgment) are legally binding even if they appear to be unreasonable from a medical standpoint. The right to self-determination has a clear legal definition in Austria and is also formulated in criminal law².

Non-binding Declaration of Intent

If we accept that a patient of sound mind and judgment now has the right to decide whether or not a medically indicated measure should be performed, then it should also be accepted that a refusal (subject to certain prerequisites) continues to be effective and binding in the future.

Resistance on the Part of Physicians

In practice, however, we have seen repeatedly that precisely in the case of anticipatory declarations of intent there is great resistance on the part of the medical community to accept their binding nature. This shows that many physicians do not believe their patients capable of forward-looking self-determination. Rather, the physician is expected to decide based on his or her own perspective and the point of view of his or her own values. This neglects the fact that the presumed intent of the patient should be ascertained in such situations and that the physician should proceed accordingly. In medical practice, patients are compelled to make anticipatory decisions every day: e.g., for each routine surgery under general anaesthesia, where the patient must give his or her consent to the scheduled operation. This procedure is accepted because surgery is performed very soon after the consent is given. But the basic situation is identical when patients give their consent for a later point in time at which they are no longer conscious.

Historical Background

The year 2001 was marked by intensive discussions among experts and in the media on the topics of hospices, euthanasia/palliative care for the dying, and living wills. On 29 May 2001, the National Council conducted a parliamentary session to consider the topic "Solidarity with the dying – Aspects of humane palliative care for the dying in Austria". Apart from numerous technical experts, patient advocates were also invited to speak about their experiences.

² § 110 of the Penal Code [StGB]

Based on this debate, the National Council adopted a resolution to the effect that a practically oriented solution should be developed for living wills based on the currently applicable law and that the need for legislative action should be determined.

Austria's Ministry of Social Security and Generations³ set up a working group based on this resolution to deal with the task. In the first phase of its work, this working group, which also included patient advocates, sought to work out a guideline that was not legally binding in order to provide physicians and patients with a guiding principle. Despite extensive work on the subject matter and detailed drafts, no document was finalised, since part of the working group⁴ refused to give up its strong fundamental resistance to living wills *per se*.

The Federal Ministry of Health therefore wrote a draft Federal Act on Living Wills on the basis of the preliminary work and results of the working group and submitted it for general consideration.

This draft was then revised by the Federal Ministries of Health and Justice. Their opinions were taken into account in the audit procedure and most considerations from further sessions with experts were also taken into account (but definitely with additions and changes⁵).

A New Federal Act

Ever more individuals, patients and residents of care facilities have expressed their desire to make a living will in recent years. Over the past few years, the Lower Austrian Association of Patient Advocates⁶ and other institutions⁷ have already been offering extensive information and support materials (forms, working aids, and instruction card). In fact, it was legally admissible to create a living will even before the new Act.

Some statutory provisions, such as the hospital laws⁸ or the Patient Charter⁹, made reference to this possibility. Naturally, the laws applicable to date were drafted such that

³ Now Federal Ministry of Health and Women

⁴ The representatives of the Austrian Chamber of Physicians were not willing to give up their fundamental opposition in the end.

⁵ Such as the new "legal authentication" through specific legal professions

⁶ www.patientenanwalt.com

⁷ Such as Hospiz Österreich

⁸ § 10.1, line 7 of the (Federal) Hospital Act (KAKuG) states: "in the case history, it is necessary to document dispositions by patients in which patients first expresses their desire not to undergo specific methods of treatment in the event that they loses their capacity to act ..."

⁹ Art 18 of the "Patients' Charter": "Patients shall have the right to deliver a statement at the start, through which they express their wishes for the omission of a treatment or specific methods of treatment in the event they become incapable of acting, in order that these wishes shall be taken into account as far as possible when future medical decisions are taken."

they gave the impression that previously written living wills were not legally binding but merely expressed information, preferences, or orientation. Moreover, several fundamental issues were not legally regulated and therefore open to numerous interpretations (with rather different results).

Such issues include:

- formal requirements
- period of validity
- legally binding nature
- content

The new Federal Act therefore regulates:

- general requirements for the validity and possible contents of living wills,
- the possibility of a legally binding or non-binding living will,
- prerequisites and formal requirements for binding living wills,
- the significance of (non-binding) living wills in ascertaining the presumed will of the patient,
- the period of validity of the binding living will and
- protection against misuse of living wills

The new Act will assist both patients and residents of care centres in exercising their right to self-determination but also the members of the healthcare professions; in particular; it will help physicians clear up their legal uncertainties and thus enhance legal certainty.

The living will as a bridge of communication

Assuming that the physician-patient relationship should be a “therapeutic partnership”¹⁰ based on certain basic rules, workable and meaningful decisions on treatment cannot be made without cooperation between these partners.

Using their technical expertise and experience, physicians explain the advantages and disadvantages of a treatment and the possible alternatives.

¹⁰ Die Therapeutische Partnerschaft, published by Dr. Michael Peintinger, Springer Verlag, ISBN 3-211-83792-2

This information allows patients to decide (insofar as they are of sound mind and judgment) whether to undergo a treatment and, if so, which of the proposed measures to select. The decision is influenced not only by medical information but also by the patient's very own value system. It is this interaction that is described by the term "therapeutic partnership" ("shared decision making"). The living will is a valuable tool to facilitate and intensify these valuable mechanisms when the patient is deprived of his or her capacity of sound mind and judgment. The living will therefore acts as a bridge of communication.

People eligible to establish a living will

A living will may be set up only by the individual him or herself, not by his representative or guardian. Establishing a living will is therefore a highly personal right. Persons who wish to establish a living will must therefore be of sound mind and judgment. They should therefore be able to understand the reason for the rejected treatment and its significance and to make up their own mind on the basis of this understanding.

People who are appointed a guardian because they are not capable of entering into legal transactions may establish a living will themselves provided they are of sound mind and judgment.

People who are unable to write

People who are of sound mind and judgment but cannot write or have lost the ability to write (e.g., because of a physical disability), may nevertheless establish a living will. The person establishing the living will must make a mark (i.e., an abbreviated form of a signature, as a substitute for a full signature) in the presence of two witnesses. One of the witnesses must write the name of the person establishing the will under this mark. The first and second witness then sign their names and thereby testify to the procedure. If the person establishing the living will cannot even make a mark, the living will must be recorded by a notary (or court of law)¹¹.

¹¹ § 886 of the Austrian Civil Code (ABGB)

The Contents of a Living Will

A living will is a declaration of intent through which a patient refuses one or more medical treatments. Such a declaration of intent may be issued by persons who are already ill or not yet ill. With a living will, only certain (specifically named) medical treatments can be rejected. The basic supply of food and liquids is part of the care and cannot be refused. However, it is possible to refuse insertion of PEG tubes (and thus the introduction of food and liquids), since special surgery is required to insert a PEG tube.

Wishes for treatment (e.g., a certain type of pain relief) may also be expressed in a living will, if the following prerequisites are satisfied:

- medical indication
- actual feasibility
- legality

“Desired treatments” related to measures for direct active euthanasia are still prohibited by law and cannot form part of the living will. Such measures are actions that are directly intended to shorten or terminate life.

Other contents are possible, such as the appointment of a person of confidence or appointment of specific persons to whom no information may be given concerning the state of health.

For any future appointments of guardians, suggestions may also be made to the effect that a certain person be appointed as a guardian by the Guardianship Court that registers the living will. Such instructions are important to the Guardianship Court and are observed whenever legally and practically feasible.

Types of living will

There is a non-binding living will and a binding living will.

There are no formal requirements for the establishment of non-binding living wills. The non-binding living will allows the physician a certain freedom of interpretation. In this case, the physician is not absolutely required to comply with the patient’s oral or written refusal of a treatment if there are concrete and understandable indications (in the context of interpreting the presumed will of the patient) that the patient would have wished otherwise in the actual situation than what he or she had expressed orally or in writing in the living will.

In contrast, a binding living will does not allow the physician any margin of discretion in interpreting the presumed will of the patient. The physician is absolutely required to refrain from giving the medical treatment described in the living will. There are strict legal requirements for the establishment of binding living wills (e.g., the written form requirement).

The Effective Date of a Living Will

A living will becomes effective once the patient is no longer of sound mind and judgment, or no longer capable of self-expression.

As long as the patient is capable of formulating his or her will and issues declarations of intent, these current expressions of will are applicable.

Establishing and Revoking Living Wills

The establishment of a living will is subject to certain prerequisites that are much less stringent in the case of a non-binding living will than in a binding living will. In particular, the formal requirements for the binding living will are intended to make clear to the person establishing the will that he or she is taking a step with medical and legal consequences (warning function).

In contrast, any living will can be revoked at any time without requiring any formalities. The revocation may be either oral or written.

Suggestive actions, too, i.e., actions from which an intended revocation may be inferred (such as a nod of the head in response to a pertinent question) also serve to revoke the patient's living will.

Prerequisites for binding living wills

In terms of form and content, there are strict requirements and prerequisites for binding living wills:

- they must be drawn up in writing,
- the medical treatment must be specifically described or clearly implied by the overall context of the living will,
- the living will must show that the patient was fully aware of the consequences of the living will,

- the physician must have given a comprehensive explanation with medical information about the nature and consequences of the living will, and this must be documented.

Further prerequisites for a binding living are the establishment of the living will by:

- a legally qualified collaborator or patient advocate,
- an attorney or
- a notary

Period of Validity of a Binding Living Will

A binding living will remains in force for a period of 5 years. This means that the living will must be renewed after 5 years (while complying with the formal requirements) in order to remain effective.

However, if the patient loses his or her soundness of mind and judgment, or his or her capacity of self-expression within five years (and this special case is expressly governed by law), the binding living will continues to stay in effect anyway. As the patient cannot renew the living will in this case, the will remains binding despite the expiration of the five-year period. For such special cases, no “term of expiration” is stipulated for the binding effect of the living will.

If the patient remains of sound mind and judgment, however, and fails to renew the will in a timely manner (within five years), the binding living will is transformed into a non-binding living will.

The Non-binding Living Will

A living will that does not satisfy all the formal requirements is not binding but remains indicative when ascertaining the patient’s intent. This means that the contents of a non-binding living will are not irrelevant but must be taken into account in the physician’s decision.

A non-binding living will can be established without formal requirements and therefore also orally. Such an oral living will must be documented by the healthcare personnel in the case history.

It is advisable for a non-binding living will to be established in writing, too (based on the present form), also with a medical consultation. In addition, it should be renewed at least every five years.

As a general principle, the more formal requirements are satisfied by the non-binding living will, the more closely the non-binding living will approximates the binding living will.

How to Establish a Living Will

The procedure to establish a living will, as it may typically appear, can be outlined as follows:

Establishing the living will with a physician in private practice

At first, the patient must decide whether and why he or she wishes to establish a living will. Are there specific considerations or rather vague anxieties behind the plan? Can these anxieties be allayed by providing information or would they only be substantiated? The initial contact with a patient advocate should provide basic information about the effects of and prerequisites for a living will. After the initial consultation (usually by phone), the folder with the auxiliary materials is sent so that patients can read the information at their leisure and discuss it with persons of trust.

After initial consultation with the patient advocate (or notary or attorney), the next step leads the patient to an examining physician, for a comprehensive discussion of the medical subject matter, which represents the “core” of the living will. First of all, the physician should always examine (both in the case of non-binding and binding wills) whether the patient is of sound mind and judgment.

Then, a comprehensive information session should take place, especially with respect to the rejected actions, the consequences of the refusal, and any possible alternatives. The major challenge will presumably be to deal with the relevant person’s concerns and anxieties in a highly individualised manner, while avoiding a direct influence through intentional or unintentional manipulation of the discussion at all costs. After this in-depth discussion of the background and consequences, the physician must also be capable of documenting the reasons for which the patient considers the consequences of the living will to be desirable.

Apart from explaining and documenting the prerequisites and providing clarification, another essential task of the examining physician is to describe as specifically as possible, together with the patient, the rejected measures and the circumstances under which they are to be refused. For this service (which is not covered by statutory health insurance), efforts are underway to establish a standard fee or standard fee guidelines.

Patients who wish to establish a binding living will then get in touch with a patient advocate, notary or attorney so that they can examine the will one last time to ensure completeness and comprehensibility and to obtain legal information.

Establishing the living will in the hospital or nursing home

If there is no time or opportunity to establish a living will prior to a stay in a hospital or nursing home, the living will can still be established after admission. The hospital or nursing home staff will provide the necessary help and support.

In such cases, too, it is advisable to use the forms provided and medical information and advice must absolutely be provided to help in establishing the living will.

Since the healthcare providing team is already known in this case, a binding living will is not absolutely necessary and a written non-binding living will should do just as well. This means that it is not necessary to involve the patient advocate, notary or attorney.

The physician's knowledge of the living will

With the instruction card, the patient can and should inform the healthcare personnel of a nursing home that he or she has established a living will and where it is has been deposited (e.g., with a person of confidence).

It is still necessary to investigate and discuss better technical solutions, such as storage on an e-card or filing in a register (such as the registry of objections to organ removal at the Austrian Health Institute (ÖBIG)).

The Role of Patient Advocates

According to section 6 of the Federal Act on Living Wills, one prerequisite for a binding living will is that the disposition be established in the presence of an attorney, notary or legally trained associate of the patient advocacies (sec. 11 e of the Federal Hospitals and

Health Institutions Act¹²). Before this, the patient must be given information regarding the consequences of the living will and the option of revocation at any time. This information must be provided not only the first time the will is established, but every time it is renewed.

While the physician informs about the medical consequences and alternatives, the persons indicated in section 6 are responsible for explaining the legal consequences. The explanations on the Federal Act on Living Wills go beyond this text, however. It is specified with respect to Section 6: “The primary purpose of the requirement that the living will be established before a legally qualified person is to ensure that the living will is formulated understandably and meets the requirements of this same Act.” This is task of great responsibility and a major challenge that patient advocates gladly assume.

The task of the patient advocates cannot be limited to the legally prescribed minimum, however. From the time of their creation, patient advocacy and patient representative groups throughout Austria have striven to help patients exercise their rights. Their very purpose and their most challenging task is to breathe life into the rights enumerated in the various laws and in the Patient Charter, to put the printed page into practice, and make it a reality. This requires intensive information and awareness-raising work, both with patients and with healthcare personnel.

Loss of validity of living wills

The Federal Act on Living Wills stipulates general requirements for the validity of non-binding and binding living wills. If any of these prerequisites is not satisfied, a living will shall not be implemented during treatment, regardless of whether it was established as “binding” or “non-binding”:

- The living will must be free of absences of intent, it must be declared freely and honestly and not by mistake or through fraud, deceit, or physical or mental coercion. These general contract law prerequisites¹³ for the validity of declarations of intent are taken up in the Federal Act on Living Wills to facilitate the task of members of the judiciary.
- The contents of the living will must be admissible under criminal law. In particular, this provision is aimed at the “desired treatments” of patients who request a form of direct active euthanasia in a living will. Direct active euthanasia

¹² Kranken- und Kuranstaltengesetz, KAKuG, Federal Law Gazette 1/1957

¹³ §§869 ff ABGB

is still prohibited (under criminal law) in Austria and should not be brought back in through the “backdoor” of the new Federal Act on Living Wills.

- The living will becomes invalid if the state of the art in medicine has changed so substantially since the time of establishment or the most recent renewal of the living will that the patient’s original declaration is no longer sufficient to cover and include the present medical decision (*clausula rebus sic stantibus*).

This provision will no doubt entail some crucial problems of interpretation since the vague legal concept of “substantial change” will very likely lead to serious discrepancies in interpretation among the various members of the justice system. In any case, those who invoke this provision of the law in order to establish the invalidity of a living will, will have to prove all the circumstances that have led up to this decision, conclusively and in a comprehensible manner.

Emergency Care

Measures of emergency medical care must not be impaired by the new Federal Act. In a medical emergency, the top priority is not to look for the living will but rather to take all medical measures urgently necessary to preserve health or save lives.

If, by way of exception or by coincidence, healthcare personnel happen to be aware of the contents of a living will in a medical emergency, then the patient’s declaration of intent is applicable and should be observed.

Protection against Misuse

The Federal Act on Living Wills contains protective legal provisions intended to prevent the misuse of living wills.

Anyone who makes access to facilities of treatment, care or nursing or the procurement of such services dependent on the establishment or the non-establishment of a living will is guilty of an administrative offence.

Assistance with the Establishment of Living Wills

Experience in Austria and other European countries show that patients and healthcare personnel are overburdened and confused when various establishments and institutions offer a large number of different forms for the establishment of living wills.

The Lower Austrian Association of Patient Advocates have therefore launched a project across Austria to develop a high-quality, recognised form that is recommended and used by the main healthcare and social security institutions. The text of this form is ready and is already being supported and recommended by the Ministry of Health and Justice, the working group of patient advocates, Hospiz Österreich, Caritas, the Austrian Chamber of Notaries, the Austrian Bar Association, and the Austrian Medical Chamber.

This form and other resources can be received free of charge in a folder from the Lower Austrian Association of Patient Advocates (www.patientenanwalt.com). The folder contains a form, a manual, support materials, an instruction card, and a copy of the Federal Act.

The aim of this folder is to create as much clarity as possible. Clarity should be provided for all those involved– both patients and medical personnel – concerning the legal prerequisites and consequences, as well as the declarations of intent stipulated by the living will.

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