

# **Patient Autonomy despite Inability to Give Consent – Legal Alternatives in Germany**

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## **[Abstract]**

Nowadays after longterm developments, information of the patient and his given consent are legal and medico-ethical principal conditions for any medical treatment. If the patient is not able to give his consent, a legal guardian, a former empowered attorney, written advance directives of the patient or his supposed will can substitute for the consent. As these surrogates have different advantages and disadvantages, they have to be balanced. The paper discusses the long-standing ethical and legal discussions and describes the situation after the adoption of a law on patients' arrangement by the German Bundestag.

## **1. The Principle of Patient Autonomy – Development and Regulation**

The need to obtain informed consent to medical procedures has not always been common practice; in fact – in terms of the history of medicine as a whole – it is a relatively young phenomenon. In the early days of Hippocratic tradition, it was the physician alone who determined what was good for the patient and what, accordingly, had to be done. The doctor was guided by the welfare of the patient, such as it was defined by medicine and a broad consensus within society.

All that changed on account of two developments, one being the enormous advance in medical treatment options – from the operation under anesthesia, the medicinal and mechanical support or even substitution of pathological processes, to the present-day replacement of malfunctioning organs

by way of transplantation medicine.

As a result, many diseases can be treated and life prolonged, sometimes even to a point where the sense and desirability of such efforts becomes questionable. Not all that is technically feasible is likewise medically indicated. Hence, even a patient's objective well-being is no longer so easy to ascertain.

The second development lies in the individualization and concomitant differentiation of life styles and life aims. In ethically and culturally homogeneous societies, the prevalent idea of what constitutes a good and meaningful life, and the ways of achieving this, tend to be quite consistent. With the progressive juxtaposition of differing traditions, religions and, indeed, images of humanity, there are no longer any uniform answers to the questions entailed in illness and disability.

For instance, the fundamental query: what is death, what comes thereafter? Is death the end of everything, or part of a cycle leading to rebirth, or is it the "gateway to everlasting life", as Christians say? We can no longer deliver convincing and binding replies to these and other issues for society as a whole, tempered by European religious wars, and have therefore resorted to replacing a collective substantive truth by the principles of freedom of faith and conscience as well as mutual tolerance.

One might regret this, emotionally, and go on yearning for eternal and absolute truths, but reality has no doubt compelled the State, law and also the ethics of the medical profession to regulate no longer life itself but (only) human co-existence.

In the more or less immediate wake of these general transitions and reflections, the classic paternalist-benevolent basic pattern of doctor-patient relationships was relinquished in favor of patient autonomy, first in the United States, then in Europe and Asia. In the Federal Republic of Germany, the *Deutsche Ärztetag*, the annual German Medical Assembly representing the medical profession, in 1988 decided on an additional Section 1a to the Medical Association's (model) "professional code of conduct for German physicians" whereby "the physician is obliged to respect the patient's right to self-determination"<sup>1</sup>, thus implementing what had been the established practice of the courts for decades.

Nearly another decade later, in 1997, this code of conduct was revised again to confirm the change from the *welfare* to the *will* of the patient as the uppermost precept governing medical decisions. Now it reads, "[E]very medical treatment undertaken must seek to guarantee human dignity and to respect the personality, will and rights of the patient, in particular the right of self-determination"<sup>2</sup>.

According to both the current code of conduct for physicians and the consistent interpretation of the contract governing medical treatment, any medical intervention in principle requires the patient's prior consent following personal consultation. The latter includes the provision of information on the diagnosis and prognosis as well as the pending procedure.

Yet the scope, aim and purpose of patient information continue to be viewed disparately by degrees. The German Medical Association claims a so-called therapeutic privilege for its physicians whereby information about an illness may be restricted or even contraindicated for therapeutic reasons. Accordingly, the physician must "consider the patient's physical and mental condition upon disclosing the in-

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<sup>1</sup> Deutsches Ärzteblatt 1988, p. B-1089.

<sup>2</sup> § 7 (Behandlungsgrundsätze und Verhaltensregeln), Abs. 1 der (Muster-) Berufsordnung für die deutschen Ärztinnen und Ärzte. Deutsches Ärzteblatt 1997, pp. B-1920 et seq.

formation”<sup>3</sup>. Formerly, court rulings had deemed this justified in cases, and only in cases, where such a disclosure of the nature of an illness would entail serious *and irremediable* damage to the patient’s health.<sup>4</sup> According to a resolution adopted in 1999 by the health minister conference of the German federal states, physicians must go beyond their duty to inform, and answer the patient’s questions “truthfully, comprehensively and understandably”<sup>5</sup>; subsequent guidelines stating this requirement were also signed by the German Medical Association in 2003.<sup>6</sup>

While legal experts emphasize the patient’s right of personality and self-determination in justifying his need of information, the German Medical Association still adheres to its Hippocratic traditions when it declares that “information [is to] place the patient in a position ... to reach a decision that is reasonable also from a medical viewpoint”. The following discourse seeks to make clear, however, that the physician is principally bound by the patient’s decision to reject treatment, “also if this is unreasonable or even indefensible from a medical standpoint”<sup>7</sup>.

Information to patients must be provided in personal consultations; forms and information sheets alone do not suffice. Nor is it admissible to delegate this task to staff members who are not physicians. The doctor should inform the individual patient in a circumspect and comprehensible manner, making sure the patient has understood him linguistically and content-wise.

Addressee of information and declarer of consent is normally the patient himself. If, however, this person is not competent in terms of medical law to give consent because he lacks the natural capacity of discernment and control needed to conceive the manner, significance and consequences, including risks, of a proposed measure and to determine his will accordingly, an agent authorized by him or a legal representative appointed by court can and must be informed in his place and consent to that measure.

Information must be rendered on the prospective therapeutic procedure, its normally-to-be-expected consequences as well as its not-to-be-ruled-out risks. The latter involve not only typical risks of the procedure in their approximate statistical frequency – the so-called complication rate – but also risks of specific relevance to the patient concerned, even if they are very rare. This is to enable the patient to reach a decision after having weighed all circumstances of importance to his case. If several medically tenable options are available, for example nonsurgical therapy *versus* immediate operation, the patient must be informed of these as well so that he can make his decision accordingly.

The patient must be informed while still in full possession of his cognitive faculty and decision-making ability; he must be left enough time for consideration if the urgency of a measure permits this; and he must not come under decision-making pressure, meaning he should be informed no later than on the day before the medical intervention.

Information enables the patient to embrace his autonomy, yet in exercising his right to self-determi-

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<sup>3</sup> Empfehlungen zur Patientenaufklärung. Deutsches Ärzteblatt 1990, p. B-940, no. 6.

<sup>4</sup> Cf. decisions of the German Federal Court of Justice in Civil Matters: Entscheidungen des Bundesgerichtshofes in Zivilsachen. Vol. 19, pp. 176 et seq. (my italics, U. L.).

<sup>5</sup> Patientenrechte in Deutschland heute. Bremen 1999, p. 10.

<sup>6</sup> Patientenrechte in Deutschland. Leitfaden für Patienten und Ärzte. Berlin 2003, p. 12.

<sup>7</sup> Empfehlungen zur Patientenaufklärung. Loc. cit., no. 4.

nation he may choose to decline such information. Being informed is a patient's right, not an obligation, and it would be an oxymoron to force this liberty upon him.

## 2. Alternatives in the Event of the Patient's Inability to Give Consent

### 2.1 Court Appointment of a Legal Representative

The legislation governing representation<sup>8</sup>, embodied in the Fourth Book (Family Law) of the German Civil Code (*Bürgerliches Gesetzbuch*, BGB)<sup>9</sup>, stems from 1992<sup>10</sup> and has so far been amended twice, in 1999<sup>11</sup> and in 2005<sup>12</sup>. Essentially, it provides that legal representatives appointed by the Court of Guardianship (at the district courts) are entitled to act legally in specified areas of life on behalf of persons of full age who themselves are unable to do so owing to a mental illness or a physical, mental and emotional disability (including the mental consequences of geriatric decline, such as dementia). The patient's right of self-determination is to be retained as far as possible.

The court becomes active either upon application of the ill or disabled person himself, even if he is legally incompetent, or *ex officio* at the suggestion of his next of kin, other loved ones, or also the staff of social, nursing or medical facilities. The court appointment of a legal representative is of lower priority than the authorization of a healthcare proxy by the patient himself. The court may, however, appoint a legal representative to oversee the proxy.

The legal representative's scope of responsibility may, as deemed necessary by the court, include property administration, residence and housing issues, postal and telephone traffic, or healthcare matters. He must moreover seek court approval for a number of serious decisions and measures, for example the vacation and dissolution of a rented apartment, or freedom-depriving arrangements including committal to an institution. This also applies to medical measures in the event of a justified risk that the patient could die or suffer grave and longer-lasting health damage if – according to the amended law (Section 1904(4) BGB) – the legal representative and the attending physician are in disagreement as to the patient's will (including decisions on the adoption and termination of life-sustaining measures in the case of coma patients).

Normally, the person represented may, to the extent that he is (temporarily) competent or capable of consent, continue to make his own dispositions. If necessary to avert a considerable danger to his person or property, the court may further order that a patient's declarations of intent require the consent of his legal representative (so-called reservation of consent).<sup>13</sup> Exempt therefrom are minor transactions of daily life such as buying a newspaper or such strictly personal matters as entering into marriage or making a will. Every seven years at the latest, the court of its own accord reviews the necessity of pro-

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<sup>8</sup> Cf. generally Seichter, J.: Einführung in das Betreuungsrecht. 3rd ed. Berlin etc. 2006, 349 pp.

<sup>9</sup> Of 1896 as amended on 2.1.2002, BGBl. I, p. 42, rectified on pp. 2909 and 2003, p. 738.

<sup>10</sup> Cf. Gesetz zur Reform des Rechts der Vormundschaft und Pflegschaft für Volljährige (Betreuungsgesetz), dated 12.9.1990, BGBl. I, p. 2002; effective as from 1.1.1992.

<sup>11</sup> Cf. 1st amendment: 1. Betreuungsrechtsänderungsgesetz, dated 25.6.1998, BGBl. I, p. 1580; effective as from 1.1.1999.

<sup>12</sup> Cf. 2nd amendment: 2. Betreuungsrechtsänderungsgesetz, dated 21.4.2005, BGBl. I, p. 1073; effective as from 1.7.2005.

<sup>13</sup> Under the former legal situation, that was the main difference between curatorship and guardianship.

longing its stipulations.

In selecting the legal representative, the court must comply with any recommendation made by the person to be represented, provided this does not run counter to his welfare. The court cannot reject the recommended candidate on the sole ground that someone else might be more suitable. It is moreover bound to accept not only recommendations made under the current procedure but also nominations stated earlier, for example in a so-called directive of representation, unless the person to be represented recognizably does not wish to uphold this. Likewise, the court is to consider any earlier or currently voiced rejection of a legal representative.

If the person to be represented fails to recommend someone who can be appointed his legal representative, the court in making its selection must pay regard to that person's relational and other personal ties, notably his parents, children, spouse or partner in life. In 2004, family members were appointed representatives in a good two-thirds of all cases. If an eligible candidate cannot be found from within this circle, representation is to be entrusted to another appropriate appointee prepared to accept this responsibility on a voluntary basis. Only if all hitherto mentioned options are absent is a professional or an institutional (association or authority) representative to be appointed.

In making its selection, also from among the next of kin, the court must consider potential conflicts of interest. These might involve inheritance issues or the problems of well-intended but unduly constrictive overprotection.

The law precludes the appointment of any legal representative who is in a state of dependence or otherwise in close contact with a nursing home or other institution in which the ill or disabled person resides or to which he has been committed. This applies in departure from the above-mentioned principle of the represented person's right of recommendation, even in cases where he expresses such a wish. The danger of conflicting interests and/or loyalties between the institution and the person requiring representation is viewed as too great.

The representative undertakes within his assigned areas of responsibility to legally attend to the affairs of the person under his charge and to look after him personally to the extent necessary to fulfill this responsibility. The affairs of the person represented are to be handled in a manner consistent with his welfare; he is thereby to be enabled, within the scope of his capabilities, to organize his life according to his personal wishes and ideas. Thus it follows that the welfare of the represented person must be determined not by objective standards alone, but by that person's will insofar as this is reasonable. The State, and so the representative it authorizes, does not have the right to seek to educate or improve the person under its care; that would contradict the general right of personality and the principle of freedom of action enshrined in the Basic Law (German constitution).<sup>14</sup>

The wishes of the person represented must be complied with according to the law insofar as this, on the one hand, does not run counter to his welfare and, on the other, can be reasonably expected of his legal representative. Hence, grounds are required not for abiding by the patient's will but for any

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<sup>14</sup> Also mentally ill patients must, according to the case-law of the German Federal Constitutional Court, be allowed "within certain limits, the 'freedom to be ill'" (ruling dated 23.3.1998, *Neue Juristische Wochenschrift* 1998, p. 1774); coercive measures are permitted solely under the legislation governing the mentally ill – *Psychisch-Kranken-Gesetze* – enacted by the German federal states.

departure therefrom. This likewise applies to earlier expressed wishes unless the patient recognizably does not want to uphold these.

Before the legal representative can deal with important affairs, he must discuss these with the person he represents, provided this is not contrary to that person's welfare. Finally, the representative must also strive to make use of opportunities to eliminate or alleviate the illness or disability of the person under his charge, to prevent an exacerbation of the affliction or at least mitigate its consequences.

In sum, the body of law governing representation as retained in its amended provisions tends to be of a supportive rather than patronizing nature and thus attempts to approach the aim of enabling patients to maintain a self-determined way of life.

## 2.2 *Enduring Power of Attorney*

To avoid the necessity of court appointment of a legal representative, the law provides for the so-called enduring power of attorney<sup>15</sup> which a principal may grant while (still) in good health. Requirements are that the principal is legally competent and able to appoint an absolutely trustworthy person prepared to assume the task as his legal agent in case the principal himself can no longer regulate his own affairs. The power of attorney is based on a mandate, which may also be implied, for the procurement of specified legal matters through the authorization of a proxy.

An advantage over court-ordered representation is that the principal influences his own destiny in a fully self-determined and self-acting manner, thus attaining a high degree of autonomy and avoiding any element of "objectness" still inherent in representation (in place of former guardianship).

Power of attorney can be granted as a general power for all affairs accruing or, as in the case of legal representation, be limited to selected areas of life. Another conceivable alternative is to appoint several proxies for different fields – say, an economically versed person for property issues and a person with medical experience for healthcare decisions. The principal must also specify whether or not a proxy may delegate sub-power of attorney to another agent.

A former recommendation was to have power of attorney take effect "in case I myself can no longer act owing to an illness ..."<sup>16</sup> Such stipulations are advised against today because in some circumstances it may be difficult and time-consuming to prove to an (overly) cautious business partner or medical attendant that the stipulated condition has actually occurred. Indeed, the very advantage of a power of attorney can be that in an emergency an informed and prepared agent is immediately available to make decisions on behalf of the principal and to assert these forcefully, if necessary.

The law does not generally demand that authorization be granted in writing; this is advisable, however, for the sake of clarity and provability on all sides. If the power of attorney applies to a declaration of consent to medical measures involving a reasonably expected danger to life as in the case of, say, a difficult heart surgery or the threat of grave and long-lasting health impairment resulting from an amputation, or if such consent entails measures of involuntary committal to an institution, the legislation

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<sup>15</sup> Cf. Die Vorsorgevollmacht – Erläuterungen. In: Bundesministerium der Justiz (ed.): *Betreuungsrecht. Mit ausführlichen Informationen zur Vorsorgevollmacht.* Berlin 2008, pp. 25 et seq.

<sup>16</sup> Die Vorsorgevollmacht – Erläuterungen. Loc. cit., p. 33.

governing representation calls for the written form and the express designation of these powers.<sup>17</sup> Like a legal representative, the healthcare proxy moreover requires approval from the Court of Guardianship in the pertinent cases.

Different from the private property will, the “written form” here does not necessarily signify a handwritten text; typed declarations or purchasable pre-printed forms can also be used.

For an enduring power of attorney to become known to the Court of Guardianship when it is called upon to review the appointment of a legal representative, the principal can and should have the deed recorded in the *Zentrale Vorsorgeregister*<sup>18</sup>, a central register maintained by the German Federal Association of Notaries. In spring 2006, over 300,000 authorizations were registered there.

A power of attorney does not automatically end with the death of the principal, but initially remains in effect at the expense of the decedent estate; it can be cancelled by the heirs. If the power is to be effective only until the end of the principal’s life, this can be recorded in the deed. A disadvantage here, however, is that business partners may in turn request the proxy to submit a certificate of the principal’s existence.

The enduring power of attorney takes effect in the event of the principal’s illness. If the patient is unable to give consent, the healthcare proxy must be informed like a patient. The physician must answer the proxy’s questions in an understandable, comprehensive and truthful manner. The proxy must likewise be given time for consideration – one day, as a rule, if there is no emergency necessitating immediate action. The consent given or refused by the proxy is deemed as that by the patient.

If the relationship of mutual trust between patient and proxy is still intact and the proxy acts in full accordance with the patient’s wishes, one can perhaps speak of an indirect form of self-determination – paradoxical as this might at first sound.

### 2.3 *Living Will / Advance Directive*

Within our overall theme, the following subject is the one discussed most frequently and fervently in recent times.<sup>19</sup> It looks back on a long history, changes in the views held by the medical profession, the withdrawal of a draft bill by the justice ministry, recommendations from diverse organizations, and competitive sessions of Parliament which in a lengthy and, until the end, contentious process led to the passage of a majority-supported law shortly before the end of the 2009 summer term.

The first living will to be published in Germany – originally, it was called the patient’s letter of instruction – stems from 1978.<sup>20</sup> It was formulated by a judge who wished to avoid for himself the ap-

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<sup>17</sup> Section 1904(5) BGB; similarly, Section 1906 BGB as regards committal.

<sup>18</sup> Cf. Bundesnotarkammer: Zentrales Vorsorgeregister. On the Internet under: <http://bnotk.de/Bundesnotarkammer/ZVR.html>.

<sup>19</sup> Cf. generally Kutzer, K.: *Patientenautonomie am Lebensende*. Baden-Baden 2006, 44 pp.; Meier, Ch. et al.: *Patientenverfügung. Ausdruck der Selbstbestimmung – Auftrag zur Fürsorge*. Stuttgart 2005, 183 pp.; Sahm, St.: *Sterbebegleitung und Patientenverfügung. Ärztliches Handeln an den Grenzen von Ethik und Recht*. Frankfurt/Main 2006, 265 pp.; Strätling, M.: *Die gesetzliche Regelung der Patientenverfügung in Deutschland: eine interdisziplinäre Analyse rechts- und gesellschaftspolitischer Gestaltungsspielräume im Spannungsfeld zwischen ärztlicher und sozialer Fürsorge, Respekt vor der Selbstbestimmung des Patienten, Schadensvermeidung und Lebensschutz*. 3rd ed. Bochum 2006, 48 pp.; Uhlenbruck, W.: *Selbstbestimmtes Sterben. Durch Patienten-Testament, Betreuungsverfügung, Vorsorgevollmacht*. Berlin 1997, 378 pp.

<sup>20</sup> Cf. Uhlenbruck, W.: *Der Patientenbrief – die privatautonome Gestaltung des Rechts auf einen menschenwürdigen Tod*. Neue Juristische Wochenschrift 1978, pp. 566 et seq.

parently senseless and undignified postponement of death as he witnessed it for a close relation who had been subject to the full range of life-prolonging technology. Many people's latent fear of over-treatment has not lessened over time – especially in view of the renewed, enormous growth in medical feasibility since then. Currently, over 200 versions<sup>21</sup> of living wills<sup>22</sup> exist, and about 15% of the population is estimated to have drawn up such an advance directive for themselves. The stance taken by physicians, when in doubt, to give priority to life quantity over life quality probably goes back to the classic Hippocratic precept of preserving life and the – as a rule, unfounded – fear of facing legal charges for having shortened life through omission.

The prevalent view within the organized medical profession has changed incrementally. In its recommendations of 1990 on providing information to patients and handling consent, the German Medical Association had managed to take only half a step toward accepting the written will of patients; former declarations were regarded (merely) as an “indication of the patient's presumed wishes”<sup>23</sup>, which could be placed alongside other presumptions such as classic vitalistic considerations, namely that in the last resort human beings always want to go on living.

That position was fundamentally altered in 1999. The henceforth generally recognized right to self-determination, and the acceptance of living wills as important instruments for safeguarding that right, led to the upgrading of provident declarations of patient wishes as an “essential aid to the physician's decision-making”<sup>24</sup>. In respect of their binding nature, it was now held that “the patient's wishes expressed in the living will [are principally valid], unless there are concrete indications to suggest a change in these wishes”<sup>25</sup>. With this reversal in the onus of proof as regards any change in a patient's presumed wishes, the medical profession had come closer to the reasoning of the courts.

In a “further development”<sup>26</sup> of the pertinent recommendations issued by the German Medical Association and its Central Ethics Commission in 2007, the following passage has been expressly incorporated: “Living wills are principally valid under the law in force, provided they do not demand ... anything legally prohibited” (loc. cit.). The medical profession then goes on to offer its expert assistance and cooperation in the patient's opinion- and decision-making processes and in drawing up the living will; it moreover recommends that a copy of the will be deposited with the family doctor.

For several years, the courts had already ceased to assess valid living wills as mere indications of yet-to-be-established presumed wishes, but regarded such earlier made declarations as advance direc-

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<sup>21</sup> Cf. the list compiled by May, A.: Verfügungsliste. On the Internet under: <http://www.medizinethik.de/verfuegungen.htm>.

<sup>22</sup> Cf., e.g., Bundesministerium der Justiz (ed.): Patientenverfügung. Leiden, Krankheit, Sterben. Berlin 2006, 34 pp.; Deutscher Juristinnenbund. Kommission Ältere Menschen: Patientenverfügung und Vorsorgevollmacht. On the Internet under: <http://www.djb.de/Kommissionen/kommission-aeltere-menschen>; Humanistischer Verband Deutschlands: Textbausteine zur Erstellung einer Standard-Patientenverfügung. On the Internet under: <http://www.standard-patientenverfuegung.de/patientenverfuegung.php>; Kirchenamt der Evangelischen Kirche in Deutschland / Sekretariat der Deutschen Bischofskonferenz (ed.): Christliche Patientenverfügung. Handreichung und Formular. Hanover and Bonn 1999, 23 pp.

<sup>23</sup> Empfehlungen zur Patientenaufklärung. Loc. cit., no. 11.

<sup>24</sup> Cf. Patientenverfügungen. Handreichungen für Ärzte. Deutsches Ärzteblatt 1999, p. B-2177.

<sup>25</sup> Handreichungen für Ärzte zum Umgang mit Patientenverfügungen. Deutsches Ärzteblatt 1999, p. B-2195.

<sup>26</sup> Empfehlungen der Bundesärztekammer und der Zentralen Ethikkommission bei der Bundesärztekammer zum Umgang mit Vorsorgevollmacht und Patientenverfügung in der ärztlichen Praxis. Deutsches Ärzteblatt 2007, p. B-791.

tives<sup>27</sup> which, upon occurrence of the contingency – stipulated medical condition and decision-making incapability – as such unfolded their binding effect, irrespective of any identical declarations by a legal agent. Legal representatives and healthcare proxies were (only) still allotted the task of ensuring that patient living wills were complied with and implemented; their consent or non-consent to medical interventions was no longer deemed constitutive but declaratory.

If and because living wills had come to play such an important role, there was now a broad consensus in Germany that their compilation and the conditions governing their validity be regulated in a law. It was agreed that a law fosters more widespread awareness for the applicable rules than do court rulings and provides greater legal certainty to all those involved. The first official attempt at a legislative procedure took place in 2004. At the time, the Federal Ministry of Justice presented a draft for a third amendment to the law governing representation.<sup>28</sup> The major aims of the bill were to strengthen patients' right of self-determination and enhance legal certainty.<sup>29</sup> The draft law took a very autonomy-friendly position that was highly contested in society and expert circles as well as in Parliament. The draft was withdrawn in 2005 on account of lacking prospects for a majority, and the problems remained unsolved.

Subsequently, two generally representative institutions addressed themselves to the issue: the *Nationale Ethikrat* (National Ethics Council) and the *Deutsche Juristentag* (German Association of Jurists). The Ethics Council was instituted by the then Federal Government and comprised representatives of all societal groups; the Association of Jurists was incorporated in 1860 and currently has some 7,500 members from across the entire legal profession, including judges, prosecutors, attorneys-at-law, administrative and business lawyers, and legal scholars. The items to be clarified and decided upon were recorded, respectively, in an opinion<sup>30</sup> and in resolutions<sup>31</sup>.

Thus, it was asserted, the fundamental precondition for the effectiveness of a "living will" or – in the more actual expression – "advance directive" is first of all that it has been drawn up without "lack of [its maker's] wishes", meaning its formulation must be devoid of any concrete indications for the maker's lacking ability of comprehension, judgment and expression, or for error, deception or coercion.

A second, highly contested issue was whether there should be any requirements of form and, if so, which. The underlying question of content involved weighing between a low-threshold usability of the advance directive instrument, on the one hand, and its conclusiveness, on the other. The Justice

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<sup>27</sup> Cf. Borasio, D. et al.: Neuer Beschluß des Bundesgerichtshofs. Verbindlichkeit von Patientenverfügungen gestärkt. Deutsches Ärzteblatt 2003, pp. B-1716 et seq.

<sup>28</sup> Cf. Patientenverfügungen. Verbindlichkeit bekräftigt. Bundesjustizministerin Brigitte Zypries legte in Berlin Eckpunkte eines Gesetzentwurfes vor. Deutsches Ärzteblatt 2004, p. B-2606. Cf. the draft on the Internet under: [http://www.user.gwdg.de/~ukee/bmj\\_041101re.pdf](http://www.user.gwdg.de/~ukee/bmj_041101re.pdf).

<sup>29</sup> Cf. Bundesministerium der Justiz: Informationen für die Presse. Eckpunkte zur Stärkung der Patientenautonomie. Berlin, 5. November 2004. On the Internet under: [http://www.user.gwdg.de/~ukee/bmj\\_041101pi.pdf](http://www.user.gwdg.de/~ukee/bmj_041101pi.pdf).

<sup>30</sup> Cf. Nationaler Ethikrat. Patientenverfügung – Ein Instrument der Selbstbestimmung. Stellungnahme. Berlin 2005. On the Internet under: [http://www.user.gwdg.de/~ukee/ner\\_050600.pdf](http://www.user.gwdg.de/~ukee/ner_050600.pdf).

<sup>31</sup> Cf. Beschlüsse des 66. Deutschen Juristentages Stuttgart 19. bis 22. September 2006. On the Internet under: <http://www.djt.de/index.php>.

Ministry's draft had not placed any great emphasis on form and sought to give legal effect also to oral declarations. This was now opposed by the argument that, then, spontaneous utterances made in extraordinary situations, perhaps after viewing an agitating movie on television, might have far-reaching consequences.

Both afore-cited institutions advocated writtenness as a formal prerequisite for the effectiveness of advance directives. They averred that the written form would make the declarer aware of the significance and consequences of his decision and actions and, hence, avoid the danger of unstable or ill-conceived declarations acquiring big importance. Further, the written form offered the greater guarantee for a clear and confirmable understanding of the declarer's wishes and mitigated the risk of intentional or unintentional misconstructions on the part of former listeners and later witnesses of the speaker's will. It was acknowledged that although the written form restricted the declarer, this was ultimately in his own interests. Beyond that, comparatively reliable documentations such as video recordings were also deemed to meet the given requirements.

A confirmation of signature (with costs) or even a notarization of the declaration was rejected as a precondition, as this would in effect constitute a big obstacle to the propagation of advance directives.

Further conditions of applicability specified were unambiguousness and the concrete description of the declarer's situation. Such general formulations as "a no longer bearable life" or "a treatment that has become futile" were not to suffice because they needed to be construed and, therefore, widened the scope also for disputable interpretations.

The potential reach of advance directives was vehemently discussed as to whether their refusal of any life-sustaining measure was to be limited to irreversibly terminal illnesses or at least to cases with no chance of the patient regaining consciousness. The proponents of such a limitation, the Catholic Church<sup>32</sup> and the majority of the parliamentary commission of enquiry on "Ethics and the Law of Modern Medicine"<sup>33</sup>, argued that the State was obliged to guarantee not only the right of self-determination but also the protection of life. The Justice Ministry and the two institutions saw no constitutional foundations for this stance, holding that just as the conscious patient admittedly had the right to abandon treatment at any time, this right should likewise be granted to persons who had made such an anticipatory decision in an advance directive.

A prudent measure was seen in the prior provision of medical and other expert information and advice to heighten the declarer's decision-making competence and the qualitative content of his advance directive. This was not, however, to be made a condition for the directive's binding force. Again it was pointed out that the conscious patient's right of self-determination allowed him to forgo information prior to making a treatment decision. That right was therefore not to be eclipsed for the advance directive either, although the wish not to be informed would then have to be recorded explicitly.

One proposal was to limit the duration of an advance directive's effectiveness to a specified term of

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<sup>32</sup> Cf. Stellungnahme des Kommissariats der deutschen Bischöfe zum Entwurf für ein drittes Gesetz zur Änderung des Betreuungsrechts. Dated 31.1.2005. On the Internet under: [http://www.user.gwdg.de/~ukee/dbk\\_050131.pdf](http://www.user.gwdg.de/~ukee/dbk_050131.pdf).

<sup>33</sup> Cf. Deutscher Bundestag. Enquete-Kommission Ethik und Recht der modernen Medizin. Zwischenbericht Patientenverfügungen. Kurzfassung. Berlin 2004, p. 7: „Reichweite von Patientenverfügungen“ (reach of advance directives).

three or five years if it was not brought up to date or re-confirmed. This was rejected, thus placing the directive on an equal footing with property wills, which are not subject to a time limit. The existence of an advance directive might indeed be forgotten in some instances, yet the negative consequences of its becoming invalid because the declarer failed to re-sign it were considered more serious. Even so, any such reaffirmation was recommendable to prevent doubts from arising about interim changes in the patient's wishes.

Conversely, the proposal was accepted to clarify by law that an advance directive is not binding if upon making it the patient was unable to foresee later medical advances, above all new therapeutic solutions that, had he known of them, would have led him to reach a different decision after duly considering his presumed will.

Thus an advance directive is to be implemented only if there are no concrete indications for interim changes in its maker's wishes. This applies not only to explicit revocations, which may be made informally, that is also orally, but to revocations implied on the grounds of the declarer's conclusive behavior, going as far as recognizable changes of natural volition if the patient can no longer make legally binding declarations. In so far, this concurs with the legislation governing representation whereby earlier wishes or recommendations which the patient "recognizably does not wish to uphold" become obsolete<sup>34</sup>.

There is a general consensus that it should be prohibited to make access to institutions rendering therapeutic, nursing or care services, or the receipt of such services, dependent on the existence or non-existence of an advance directive. The organizational or economic interests of such institutions should not be allowed to detract from the right of self-determination.

Agreement moreover stands firm on demands to expand palliative medicine and strengthen the hospice movement because these enhance the potential for self-determination. The binding nature of advance directives has not been extended to enable patients to elude quantitatively inadequate or qualitatively poor medical attendance. Rather, their sole purpose is to avoid excessive therapies which in the patient's view only serve to prolong the dying process. Meticulous care must nevertheless be taken to ensure that an unavoidable potential for abuse does not become real.

To make sure that advance directives can be located and used for decision-making in every case, they may be referred to in the aforementioned application for registration of an enduring power of attorney. In this way, they become known as soon as an agent (legal representative or proxy) is called upon to take action. In addition, there are many smaller and larger private suppliers who, after giving advice and drawing up the advance directive, also offer (at a cost) to register and deposit the document and, subsequently, to convey it to medical and nursing institutions. As a rule, these firms hand out wallet-sized cards with their phone number and provide round-the-clock information service.

Following the fact-finding process, three multi-partisan parliamentary groups introduced their re-

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<sup>34</sup>Thus the same wording is found in Sections 1897(4) and 1901(3) BGB.

spective draft laws into the Bundestag.<sup>35</sup> As is customary for medical-ethical issues<sup>36</sup>, the bills were debated and then voted upon on a cross-party basis.

Common to all drafts was that they elaborated advance directives in a new statutory body of law and attributed principal legal validity to the preparatory decisions these directives establish as regards consent or non-consent to medical measures in the event of the declarer's inability to do so. There was moreover a consensus that the revocation threshold be set as low as possible and that natural (instead of legal) volition suffice to invalidate the directive. A third point of agreement was that the Court of Guardianship must be called on at least in case of any dissent between attending physician and legal representative/proxy over the directive's applicability to a current situation.

One draft (*Zöller* bill) submitted by MPs from the Christian Democratic Union (CDU) and one MP from the Social Democratic Party (SPD) did not go beyond these minimalistic specifications because, it was argued, "life and death in their complexity cannot be standardized and defy blanket categorization" (p. 3). In seeking to avoid schematic solutions, room ought to be left for viewing individual cases in a dialogue between attending physician and legal representative or proxy.

A second draft (*Stünker* bill) submitted by MPs of the SPD, FDP (Free Democratic Party), the GREENS and THE LEFT emphasized the general importance of self-determination, regardless of the type and stage of illness, for both current decisions and advance directives. The State, it said, basically had neither the right nor the obligation to protect individuals from themselves (cf. p. 13). As a formal requirement, the bill advocated the written form with the aim of "warning those concerned against making rash and imprudent declarations" (p. 25); such formality would also serve to clarify the writer's wishes. Soliciting expert advice prior to drafting the directive was deemed recommendable but was not to constitute a condition for validity so as not to raise the access threshold. However, as in the case of current decisions, the maker of an advance directive could and should, to ensure direct effectiveness, document that he had declined information.

At the other end of the scale was the first version of a draft submitted by CDU, SPD, GREENS and FDP members (*Bosbach* bill). Its declared objective was to take equal account of "the individual's right of self-determination and the State's duty to protect life" (p.1). At the time, this point was mainly reflected in the unconditional limitation of an advance directive's possible reach: the abandonment of "life-sustaining treatment is in principle possible only in cases of irreversible disease progression" (p. 2); an exception was nevertheless made for patients who "with a probability bordering on certainty, despite exhaustion of all medical possibilities, [will] never regain consciousness" (loc. cit.). This tactical effort to gain a parliamentary majority combined two different basic positions and caused the draft in itself to become inconsistent. *If* the protection of life in the case of non-fatal disease courses limits self-determination, why then should exceptions be made for comatose or severely demented patients (cf.

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<sup>35</sup> Abg. Zöller et al.: Entwurf eines Gesetzes zur Klarstellung der Verbindlichkeit von Patientenverfügungen (Patientenverfügungsverbindlichkeitsgesetz); Abg. Stünker et al.: Entwurf eines 3. Gesetzes zur Änderung des Betreuungsrechts; Abg. Bosbach et al.: Entwurf eines Gesetzes zur Verankerung der Patientenverfügung im Betreuungsrecht (Patientenverfügungsgesetz). All drafts are found online under: [www.aem-online.de/main.htm](http://www.aem-online.de/main.htm).

<sup>36</sup> The amendment of the law on abortion of 1992 and the law on the donation, harvesting and transplantation of organs of 1997 were also adopted without any obligation to vote in accordance with party policy.

p. 18).

Furthermore, this basic paradigm raised the question of whether life-prolonging measures were even still medically indicated for infaust prognoses. *De facto*, regulating advance directives along these lines would then have largely gone back on the verbally conceded aim of self-determination.

The principle *in dubio pro vita* (when in doubt favor life) was subsequently reflected in the following criteria: the non-binding quality of advance directives if the declarer was unaware of feasible medical options and would have made another decision had he known of them; the regular convening of an advisory council, including care attendants and persons close to the patient, “to consult with the legal representative and the treating physician about non-consent or revocation” (p. 6); and the reference without exception to the Guardianship Court for the abandonment of life-sustaining measures in cases of irreversible unconsciousness, even if physician and legal representative are agreed on these measures.

The officially submitted version of the *Bosbach* draft<sup>37</sup> (following the Austrian model<sup>38</sup>) dropped the limitation of scope to the commencement of the dying phase for the one constellation that if, after having obtained medical advice, the declarer established his advance directive in writing before a notary who informed him of its legal effects and revocation options, and such notarization is not older than five years or has been confirmed in writing (so-called qualified advance directive).

An “Arranged Debate”<sup>39</sup> for general orientation and exploration was conducted in the Bundestag at the end of March 2007, in the run-up to the actual legislative procedure. It failed to produce a rational line of reasoning aimed at synthesis, but showed that the subject matter – for good or bad – tended to focus on questions of faith and moral issues.

Following deliberations in the leading parliamentary law committee and an expert hearing,<sup>40</sup> the three drafts approached one another on selected issues<sup>41</sup>, yet the motions could not be integrated. Thus, the *Zöller* bill incorporated medical counseling as a directory provision; the *Bosbach* initiative dropped notarial involvement, no doubt to facilitate reciprocal assent; and the *Stünker* group supplemented its bill by a section on “discussion [between physician and patient representative] to ascertain the patient’s wishes” (Section 1901b), in an effort to counter reproaches of “automatism” and thereby play to the *Zöller* camp.

Notwithstanding such signals and the increased emphasis of mutual respect, the debate remained contested among all groups until the end<sup>42</sup>, up to a point where not even a consensus on the sequence

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<sup>37</sup> Bundestags-Drucksache 16/11360. Online under: <http://dip21.bundestag.de:80/dip21/btd/16/113/1611360.pdf>.

<sup>38</sup> Cf. Bundesgesetz über Patientenverfügungen (Patientenverfügungs-Gesetz – PatVG). BGBl. I für die Republik Österreich 2006, 55; Körtner, U. H. et al. (eds.): Das österreichische Patientenverfügungsgesetz. Vienna 2007.

<sup>39</sup> Online under: <http://dip.bundestag.de/btp/16/16091.pdf>.

<sup>40</sup> Cf. protocol of the 128th session of 4 March 2009 (in German). Online under: [http://www.bundestag.de/ausschuesse/a06/anhoerungen/45\\_Patientenverf\\_gung/05\\_Wortprotokoll.pdf](http://www.bundestag.de/ausschuesse/a06/anhoerungen/45_Patientenverf_gung/05_Wortprotokoll.pdf).

<sup>41</sup> Cf. Beschlußempfehlung und Bericht des Rechtsausschusses, dated 8.6.2009. Online under: <http://dip21.bundestag.de:80/dip21/btd/16/133/1613314.pdf>.

<sup>42</sup> Cf. protocol of the 227th session of 18 June 2009 (in German). Online under: [http://www.bundestag.de/bic/plenarprotokolle/pp\\_pdf/16227.pdf](http://www.bundestag.de/bic/plenarprotokolle/pp_pdf/16227.pdf).

of voting on the individual bills could be found, requiring the plenum to decide that as well<sup>43</sup> (with 309 to 258 ballots in favor of the order: *Zöller, Bosbach, Stünker*). Before that, however, there was a motion to “avoid statutory over-regulation of the advance directive”<sup>44</sup>; it was rejected by a large majority.

In the voting on factual issues, the *Zöller* and *Bosbach* bills were unable to gain majorities, whereas the *Stünker* draft was passed after the second and third sittings with 317 to 233 recorded votes and 5 abstentions. The core items of the law involve modifications to the Civil Code<sup>45</sup> in the form of two new subsections (1901(a) and (b) BGB) as well as an amendment to Section 1904 BGB. In this way, the Bundestag fulfilled its task as legislator and the many years of struggle toward achieving more patient autonomy were brought to a (preliminary) normative conclusion.

## 2.4 Presumed Wishes

The absence of all previously cited options for obtaining a patient’s currently represented or self-expressed advance declaration of will does not make the requirement of consent to medical measures obsolete or confer this duty to the patient’s next of kin; rather, the patient’s “presumed wishes”<sup>46</sup> will prevail in such cases. This legal position, which already applied previously on the basis of an “agency of necessity” (Sections 677 et seq. BGB), was expressly made binding under the three bills on the regulation of advance directives with regard to decisions on medical interventions. The patient’s presumed wishes are to be ascertained as individually as possible, using all sources available, and consist in the answer to the following question: What would the patient say if he were to say something now? Any such subsidiarily determined consent or refusal of consent is of the same legal import as an explicit declaration. Individuality and autonomy are values to be held in high esteem – albeit somewhat hypothetically – in accordance with the image of humanity expounded in European civil philosophy, for example by Kant.

When determining a patient’s presumed wishes, the first step is to obtain an overview of all personal information available, consisting of his earlier oral or written utterances, especially in respect of medical treatment issues for himself or others, his religious beliefs and/or other individual moral concepts. A source for finding out the patient’s conversationally uttered wishes or specifications can be his family members or others close to him. In seeking to recall and convey previous remarks, all persons involved should, however, bear in mind that it is the will of the patient and not their own wishes and ideas that matter. If several factually congruent reports are on hand, this can serve to underscore their truth content, provided conspiracy can be ruled out. If there is only one witness, it will be necessary

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<sup>43</sup>Namentliche Abstimmungen: Patientenverfügung. Online under: [http://www.bundestag.de/aktuell/archiv/2009/24808527\\_kw25\\_patientenverfuegung/namabst.htm](http://www.bundestag.de/aktuell/archiv/2009/24808527_kw25_patientenverfuegung/namabst.htm).

<sup>44</sup>Bundestags-Drucksache. 16/13262. Online under: <http://dip21.bundestag.de:80/dip21/btd/16/132/1613262.pdf>.

<sup>45</sup>Cf. Drittes Gesetz zur Änderung des Betreuungsrechts, dated 29.7.2009, Bundesgesetzblatt Teil I, p. 2286.

<sup>46</sup>Cf., e.g., Knauf, C.: *Mutmaßliche Einwilligung und Stellvertretung bei ärztlichen Eingriffen an Einwilligungsunfähigen: zugleich ein Beitrag zur Patientenverfügung*. Baden-Baden 2005, 180 pp.; Verrel, T.: *Patientenautonomie und Strafrecht bei der Sterbebegleitung. Gutachten C zum 66. Deutschen Juristentag 2006, notably D. 5. entitled „Subsidiäre Geltung des mutmaßlichen Willens“*. Munich 2006, p. C 89.

to look into his motivations; any inexplicable discrepancies in his reports will render his statements worthless.

If for these or other reasons no concrete information about the patient's views on medical treatment alternatives is obtainable, an attempt should be made to clarify whether the person in question tended to favor a self-sufficient way of life or found dependency on the help of others acceptable. "Pain perception" as a pointer was deleted from the ultimately enacted bill because it was deemed so subjective that outsiders could scarcely appraise it. This criterion was thus thought unsuitable as an explicit indicator of the patient's presumed will.<sup>47</sup> Nevertheless, addressing this issue could deliver sufficiently probable insights, say, where an advance directive exists but cannot be used directly because it fails to take specific account of the given occurrence. A patient's presumed wishes can moreover be determined with the help of conclusions by analogy, these not being allowed for the interpretation of advance directives. And last but not least, nonverbal behavior and reactions may also be considered in some circumstances; although so-called body language as such is of no legal relevance, it might at times provide a clue to what the patient would formulate were he able to gain insight and express himself.

If (sufficient) evidence for surmising a patient's probable decision is lacking, his presumed will is to be determined – once again, subsidiarily – on the basis of objective criteria. Such criteria primarily consist of medical indications; to draw upon these is also justified by the fact that as a potential patient I need not express myself in advance if I wish to be treated in accordance with conventional medical rules and guidelines. If such standards are not available to the medical community, one must resort to the next higher level – that is, to general moral concepts prevalent in society or to philosophical lines of reasoning as found, say, in the Golden Rule (do not do to others what you would not like done to you) or in Kant's elaboration of the Categorical Imperative. Also conceivable is a combining of individual clues deemed too weak on their own with objective criteria. In terms of persons involved, a desirable approach for such a multi-disciplinary inquiry would be to convene the next of kin, physicians and nursing staff, cultural scientists and ethicists, as well as perhaps spiritual advisers, asking each to contribute their specific views and then arriving at a result on as broad a basis as possible.<sup>48</sup> After such a tentative draft has been accepted, persons close to the patient and – as the case may be – also caregivers could be given their say.

### 3. Advantages and Disadvantages: Options

This overview has shown that none of the substitutes can properly replace the ideal form of an individual's personal declaration made after being informed by his physician while in full possession of the ability to understand, decide and express himself. The cited alternatives have different advantages and disadvantages, which are compared in the following.

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<sup>47</sup> Cf. Beschlußempfehlung und Bericht des Rechtsausschusses. Drs. 16/13314, loc. cit., p. 20, left column.

<sup>48</sup> Perhaps the question will soon arise whether economic expertise must be included.

An important criterion for assessing the quality of alternative solutions is certainly the measure of self-determination they ensure. In this respect, court-ordered representation displays distinct limitations because both the appointment of the legal representative and his handling of the represented person's affairs are oriented first and foremost to the welfare of the sick or disabled person – before that person's wishes. Yet the question of what constitutes an individual's welfare can be aptly argued about. The State, for all its liberality, will in any case invoke its protective duty when called upon to take action.

Conversely, the principal is absolutely free in authorizing his healthcare proxy; whether the proxy will nevertheless always implement and fulfill the principal's wishes when acting as his legal agent remains but an expectation. Conflicts of interest that may have arisen in the meantime can consciously or unconsciously entail disparity between mandate and execution, for example following changes in a proxy's relationship to the principal, or through psychological stress or overreaction.

As far as ensuring self-determination is concerned, the advance directive is no doubt the best-suited instrument because it can be used – indeed, with binding effect – to spell out all legally feasible options.

As outlined above, determining a patient's presumed wishes is fraught with dangers that are apt to entail deviations from the appropriate result. Hence, although this construct favorably seeks to foster self-determination in theory, it is, by comparison, burdened with very high risks in practice.

Self-determination is not, however, the only criterion to be applied in giving preference to one of the above options. Another is the up-to-dateness of any formation or declaration of will. An interval of several or even many years between drafting and applying an advance directive can become significant on both an objective and a subjective level if personal circumstances and/or moral concepts have changed. That is why there were recommendations (not enacted<sup>49</sup>) to invalidate those parts of an advance directive affected by new therapeutic possibilities. The other three alternatives, by contrast, can include possible new developments in their considerations and weightings, and incorporate these in a current decision.

A not-so-decisive yardstick, yet one worth mentioning nonetheless, would seem to lie in the complexity of the diverse decision-making procedures – that is, in their swiftness. To be sure, giving enduring power of attorney to a healthcare proxy and drafting an advance directive can be tackled and concluded relatively quickly, notably the maker can influence the type, scope and pace of the tasks in hand. By contrast, the court appointment of a legal representative takes quite some time, even where summary proceedings are instituted – time often not available for decisions in urgent medical matters.

Determining a patient's presumed wishes can in some cases occur swiftly and without ambiguity; if, however, several persons must be consulted for information and/or complex problems must be investigated, this process, too, can prove lengthy and place a strain on both loved ones and medical staff.

Thus we see that none of the cited options is superior to the others in all of its criteria. The most likely preferences seem to be the enduring power of attorney, owing to its up-to-dateness, and the

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<sup>49</sup>In so far, it is left to the individual to consider whether such a clause should be incorporated in his advance directive.

advance directive, owing to its authenticity. If one of these two merits is of overriding importance to someone, the respective choice can be made by either authorizing a proxy or writing down one's wishes in a detailed document. If, however, justice is to be done to both values, the recommended step is to combine power of attorney with an advance directive. The latter can be implemented if nothing has meanwhile changed and the patient's will was declared for a concrete situation now occurring. If, on the other hand, due to a partially or wholly unforeseen situation the current need for consultation and decision-making arises, the healthcare proxy can – after having been duly briefed by a physician about the chances and risks of a planned measure, and having taken time, depending on urgency, to sound his opinion and intentions – give or refuse his binding consent in the name of the patient. The most recent declaration will always be valid.

The combination of an enduring power of attorney with an advance directive has thus also become the most publicized course of anticipatory action in medical decision-making matters. The recommendations and brochures on the establishment of advance directives as a rule advise declarers to appoint a healthcare proxy and, vice versa, the forms for granting power of attorney urge the principal to specify instructive guidelines for the tasks of his proxy.

If the above is accepted, it will be essential to create a setting and adopt practices in which even younger and middle-aged people are encouraged not to repress potential illness, infirmity and death, but to deal with them realistically, select their options, and take action by means of an advance directive and/or enduring power of attorney.