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# The Patient's Will – Why and for Whom?

## Forms, Formalisation, and Implementation Issues

### 1. Introduction

Approaches to death and dying vary quite a bit. On one extreme of the scale is the view that the ending of a life is something unnatural and undesirable and that anything postponing it should be promoted. In contrast, there is the belief that death is natural, which is strongly supported today through arguments emphasising a decent standard of living, a dignified death, and personal autonomy.\*<sup>1</sup> Depending on the approach that people subscribe to, attitudes towards dying may be radically different. Some would do anything to prolong life, no matter how much pain and suffering it causes, while others prefer to die and refuse even the simplest remedies that could keep them alive, such as antibiotics for bacterial inflammation of the lungs.\*<sup>2</sup>

In the past, prolongation or non-prolongation of someone's life at the individual's request was not a topic of much importance, since the level of medicine did not allow such prolongation anyway. However, the high speed of medical advancement has significantly widened the spectrum of possibilities for postponing death. In intensive care, technological replacement of the functioning of organs and organ systems with respiratory devices, circulation pumps, and dialysis-based artificial kidney apparatuses, *inter alia*, has become possible.\*<sup>3</sup> Likewise, life can be prolonged by drugs, resuscitation, and radiation-therapy procedures.\*<sup>4</sup> On the other hand, medical intervention may sometimes make the end of life or even one's life itself very miserable and painful and, accordingly, not desirable for the person concerned.\*<sup>5</sup>

If a patient does decide that he or she does not wish to receive health-care services and would prefer to die, the health-care service provider is not allowed to provide health-care services to that patient, under the principle of personal autonomy. In this case, the patient's wishes need to be respected even at such time as the patient is unable to express them – for instance, when he or she is unconscious.

For situations wherein a patient is incapable of expressing his or her intentions, many countries employ an instrument called a patient's will, also known as a living will or, more generally, a patient's directive (the German concept is *Patientenverfügung*) or an advance directive (health-care directive). The term 'patient's will' will be used throughout this article. A patient's will is a declaration (usually in writing) on what kind

<sup>1</sup> A. Soosaar. *Meditisiinietika* ['Medical Ethics']. 2nd, revised and supplemented edition. Tartu Ülikooli Kirjastus 2016 (in Estonian), p. 203.

<sup>2</sup> J.R. Williams. *Medical Ethics Manual*. 3rd ed. World Medical Association 2015, pp. 60, 61.

<sup>3</sup> A. Soosaar (see Note 1), p. 205.

<sup>4</sup> J.R. Williams (see Note 2), p. 60.

<sup>5</sup> A. Soosaar (see Note 1), p. 204.

of treatment a person wishes to receive or not to receive in a situation wherein he or she is unable to make decisions independently – for instance, in the event of unconsciousness or dementia.<sup>\*6</sup> In addition to preparing a patient's will, people may provide health-care directives for the future by assigning a substitute decision-maker (a health-care proxy) who can express the assigner's presumed intentions in a case in which he or she is unable to express the relevant decision.

The most effective means for ensuring one's personal autonomy is using a patient's will, since this document is prepared by the person him- or herself. Although patient's wills are not commonplace in Estonia, the country's legislation imposes no obstacles to their use. Also, the people of Estonia are becoming increasingly aware of their rights. People have already turned to notaries with a wish of providing notarial directives for the future that address the provision of health-care services or maintenance of their property in the event that they no longer have the capacity to exercise their will themselves.

This article discusses the role of a patient's will near the end of life and also examines the issues related to its formation and implementation.<sup>\*7</sup> The last part of the article briefly addresses instructions related to maintenance of the patient's assets in the case of incapacity to exercise the will.

## 2. The patient's will in the context of Estonian law

In some countries, the patient's will is regulated as a separate legal institution. This is the case, for instance, in the United States of America, Germany, Austria, and France<sup>\*8</sup>, but it is not in Estonia. Moreover, use of patient's wills is not common practice in Estonia, most likely on account of lack of awareness about the possibilities for their use. Although Estonian law does not specifically regulate the institution of the patient's will, the legislation currently in force does allow its use. Specifically, the legal rules on the patient's will can be derived from the requirements set for contracts for provision of health-care services under the Law of Obligations Act<sup>\*9</sup> (LOA).

Subsection 766 (3) of the LOA prescribes that a patient may be examined and health-care services provided to him or her only with his or her consent. Hence, if a patient does not consent to a health-care service, such services must generally not be provided. In a situation wherein a patient has the capacity to exercise his or her will, it is normally not difficult to clarify whether the patient wants to receive health-care services or not. However, the patient's right of self-determination means that there must be a possibility of refusing health-care services in future, even when one no longer has capacity to exercise one's will – when one is unconscious, suffering from dementia, or otherwise prevented from expressing personal intentions in this regard. Situations of this type are regulated by §767 (1) of the LOA.

That section of law sets forth that if a patient is unconscious or is incapable of exercising his or her will for any other reason and if either he or she does not have a legal representative or his or her legal representative cannot be reached, the provision of health-care services is permitted without the consent of the patient, where this is in the interests of the patient and corresponds to the intentions expressed by him or her earlier or to his or her presumed intentions and where failure to provide health-care services promptly would put the life of the patient at risk or significantly damage his or her health.

The two above-mentioned provisions, §766 (3) and §767 (1) of the LOA, *inter alia*, regulate the patient's will in Estonian law. While the LOA's §767 (1) allows, in certain cases, providing health-care services to a patient in a situation wherein that patient is incapable of exercising his or her will, the patient's will may preclude any health-care services in such situations. By invoking these provisions, a patient's will can prohibit provision of any health-care services if the following criteria are met:

- a) the provision of health-care services would per se be in the patient's interests (i.e., indicated);
- b) the patient is unconscious or is incapable of exercising his or her will for any other reason;
- c) a decision on the provision of health-care services cannot be postponed (since the absence of prompt provision of the services would endanger the patient's life or substantially damage his

<sup>6</sup> J.R. Williams (see Note 2), p. 120.

<sup>7</sup> The authors would like to thank Dr Alar Irs and Dr Raul Adlas for their invaluable contribution to this article.

<sup>8</sup> R. Frimston et al. (eds). *The International Protection of Adults*. Oxford University Press 2015, pp. 335, 373, 381–382, 415–419.

<sup>9</sup> RT I 2001, 81, 487; RT I, 31.12.2016, 7.

or her health) or postponement is impossible because the patient is permanently without the capacity to exercise his or her will;

- d) a legal representative does not make decisions on behalf of the patient; and,
- e) while having the capacity to exercise his or her will, the patient expressed in a patient's will that he or she wishes no health-care services to be provided.

Below, we provide a detailed examination of all the conditions on which application of a patient's will is predicated.

According to the first criterion, the patient's will applies only if provision of **health-care services would, in itself, be in the patient's interests**. Where a health-care service is already being provided, it must be reassessed at all times whether provision of that service serves the patient's interest. Provision of a health-care service is in the patient's interests if it is indicated for the patient and is of good quality<sup>\*10</sup>; i.e., it must not be a pointless therapy. If the service is not in the patient's interests, that health-care service must not be provided to the patient concerned or its provision must be discontinued. In such cases, the patient's will does not affect the provision of health-care services.

Where a health-care service is in the interests of the patient in its own right, the patient's will applies only **if the patient is in a condition wherein he or she is incapable of exercising his or her will**. The patient's incapacity should be assessed under §767 (1) of the LOA, the substance of which does not overlap with the definition of a person's incapacity to exercise will with regard to transactions regulated<sup>\*11</sup> by §13 of the General Part of the Civil Code Act.<sup>\*12</sup> Under §767 (1) of the LOA, patients have no capacity to exercise their will in any situation wherein they are incapable of expressing their intentions. Consequently, a patient is without the capacity to exercise his or her will when suffering from a mental disorder but also when physically or for any other reason incapable of expressing his or her intentions. If a patient has capacity to exercise his or her will – i.e., is capable of expressing his or her intentions – a patient's will would not be resorted to (even if one already exists); instead, one must proceed from the intentions directly expressed by the patient in the present. Such intentions may be contrary to those expressed in the patient's will instrument. In many cases, it may be quite easy to ascertain the patient's capacity to exercise will. Let us consider the case of a patient who is unconscious. There can be no doubt that an unconscious patient has no capacity to express will. However, there may exist borderline cases wherein determination of capacity can be quite complicated. Determination of medical decision-making capacity may be especially challenging with minors or those whose judgement has been impaired by acute or chronic illness. In addition, a patient may be able to make decisions regarding some aspects of life but not others. Also, such capacity may be volatile: in one moment, a person may be of sound mind and able to make sense of the surroundings while at other times not.<sup>\*13</sup> In borderline situations, the attending physician is in the best position to decide on the patient's capacity to express will. To date, there have been no known cases in Estonia in which a court has contradicted a doctor's decision.

The next precondition for the applicability of a patient's will involves the interest of **non-postponement of the decision to provide health-care services**. It means that the situation must be such that the health-care service provider needs to decide whether or not to provide the service. Such a situation exists in two cases. Firstly, the patient may have temporary or permanent incapacity to exercise will while failure to promptly provide health-care services would present a risk to the patient's life or substantially harm his or her health. This article focuses on the role of a patient's will in a situation wherein failure to promptly provide health-care services would endanger the patient's life, i.e., the question here is of prolongation or non-prolongation of the patient's life with the aid of a patient's will. Another situation in which a health-care service provider shall not postpone a treatment decision is that in which the patient has permanent incapacity to exercise will and a decision needs to be taken about a medically prescribed treatment. In the latter case, neither the life nor the health of the patient need be endangered for the patient's will to apply, because for a permanently incapacitated patient the decision cannot be postponed anyway since the health-care service provider is never going to have an opportunity to ask for the patient's consent. In

<sup>10</sup> *Võlaõigusseadus III. Kommenteeritud väljaanne* [Law of Obligations III: Commented Edition'] (compiled by P. Varul et al.). Juura 2009 (in Estonian), parts 8 and 10, §767 (1) Comment 3.2; A. Nõmper, J. Sootak. *Meditsiinõigus* [Medical Law']. Juura 2007 (in Estonian), p. 70.

<sup>11</sup> RT I 2002, 35, 216; RT I, 12.3.2015, 106.

<sup>12</sup> *Võlaõigusseadus III* (see Note 10), §767 (1), Comment 3.1.

<sup>13</sup> J.R. Williams (see Note 2), pp. 49–50.

contrast, where both the patient's incapacity is temporary and non-provision of medically prescribed treatment would not endanger the patient's life or substantially damage the patient's health, such treatment should not be provided, since a temporarily incapacitated patient's consent for a health-care service can be sought later, once capacity to exercise will has been restored. The health-care service provider must always be guided by the most recently expressed intentions of the patient and must determine those intentions whenever this is possible. The Estonian Supreme Court noted in its judgement 3-1-1-63-00 that the '[o]bligation to ask the patient's consent for a surgery arises from the inviolability of the physical integrity of a person'. In the case in question, a physician had been mistakenly guided by earlier consent of the patient to receive health-care services; the doctor subsequently provided a service without asking the patient for consent although she had the opportunity to do so.<sup>\*14</sup>

The next consideration is that applicability of a patient's will can be precluded in some cases **if the patient has an existing, available legal representative** who, under §766 (4) of the LOA, has the right to decide about the provision of health-care services to the patient. In this context, 'legal representative' refers to the legal representative of a patient with restricted active legal capacity (i.e., either a minor patient or an adult of restricted active legal capacity), with said representative normally being a parent or guardian of the patient. Since most adults have full active legal capacity, there is usually no need to determine the legal representative in cases of adult patients.<sup>\*15</sup> However, legal representation status does need to be determined in cases of minors and adults with restricted active legal capacity **if the patient is**, for reason of that restricted capacity, presumably unable to consider the pros and cons of a health-care service responsibly.<sup>\*16</sup> If treatment-related decisions would be made for the patient by the legal representative even if the patient were conscious, a patient's will would not be applicable. It is instead the decision of the legal representative that is to be taken into account when the health-care service provider is making sure that the decision is in the interests of the patient, as specified in §766 (4) of the LOA.

If all the above-mentioned criteria have been met, the patient's will is applicable. The patient's will expresses the patient's intentions with regard to the receipt or non-receipt of health-care services, even in a situation wherein the provision of these services would postpone death. Although, under §767 (1) of the LOA, the intentions expressed earlier by a patient or his or her presumed intentions should be ascertained (with the assistance of his or her immediate family), if there exists a patient's will, the provisions of that patient's will – as the intentions expressed earlier directly by the patient – should prevail over the explanations of family. The instrument of the patient's will is presumed to be a better expression of the patient's actual intentions, since it was prepared by that person himself or herself and hence does not depend on subjective interpretation by the patient's immediate family.

It is important to note that under Estonian law, a patient's will does not allow euthanasia, defined as termination of the life of a suffering patient in terminal condition who wishes for death by a doctor or by way of a doctor's intervention.<sup>\*17</sup> Under §113 of the Penal Code<sup>\*18</sup>, euthanasia is qualified as manslaughter and is punishable as a criminal offence. This means that a patient's will shall not prescribe that it is the wish of the patient that a health-care provider hasten the patient's death by taking active steps for this purpose. Even if a person so instructs in his or her patient's will, the doctor has no right to cater to this request. The patient's will may, however, instruct that health-care services be relinquished, in which case the doctor has the right and, indeed, obligation to comply with this wish even if it leaves the patient without the possibility of postponing death. This is not considered euthanasia.

With the groundwork laid as to prerequisites for application, we can now embark on more detailed analysis of the patient's will.

<sup>14</sup> CLCSCd 3-1-1-63-00, 30.5.2000, para. 7.2.

<sup>15</sup> *Võlaõigusseadus III* (see Note 10), §766, Comment 3.6.

<sup>16</sup> *Ibid.*

<sup>17</sup> A. Soosaar (see Note 1), p. 220.

<sup>18</sup> RT I 2001, 61, 364; RT I, 26.6.2017, 8.

### 3. Why a patient's will, and for whom

People of all ages with capacity to exercise will may be interested in a patient's will, whether ill or in full health. We all might find ourselves in a situation wherein we cannot express our intentions, in consequence of disease or accident. At the same time, we would want our wishes to receive or not receive particular health-care services to be respected. Since such incapacitation entails no longer being able to express our intentions, it would be beneficial for a patient's will to be available that discloses in advance our wishes related to the receipt or non-receipt of those services.

To get some idea about the benefits of a patient's will, we should attempt to reconstruct a typical situation wherein the patient has no patient's will instrument. In a situation in which the patient is without capacity to exercise will and a doctor needs to decide on the provision or non-provision of particular health-care services, the intentions expressed earlier by the patient or his or her presumed intentions should be ascertained with the assistance of the immediate family if there is no patient's will, as is set forth in §767 (1) of the LOA. According to the law, immediate family means the spouse, parents, children, sisters and brothers of the patient, but other persons who are close to the patient may also be deemed to be immediate family if this can be concluded from the way of life of the patient. However, family members or other persons close to the patient do not necessarily know about the patient's intentions or even have the patient's best interests at heart. Also, studies have demonstrated that the family of a patient cannot accurately envisage the wishes of the patient with regard to future treatment.<sup>\*19</sup> Hence, the family may present a view of the will of the patient that deviates from the patient's real intentions, mistakenly if not actually intentionally. Likewise, it is extremely difficult to make decisions when, on the one hand, being driven by a desire to maintain the sanctity of life but, on the other hand, wanting to relieve the suffering of a loved one.<sup>\*20</sup> Moreover, the family members consulted may differ in their views in regard of the patient's wish to receive health-care services and prolong his or her life. This may lead to bitter feuds among the family, which the incapacitated patient would never want to happen.

In light of all the foregoing, a patient's will may prove extremely helpful in ascertaining the actual intentions of the patient. The very existence of a patient's will might prevent friction amongst the family. Likewise, a patient's will may bring peace of mind to the family because there then is no need to have second thoughts about whether they were able to gauge the presumed intentions of the patient accurately. Additionally, the existence of a patient's will may make the doctors' job easier as, if nothing else, they do not have to consider the opinions of the immediate family, which, again, may diverge, and give preference to one person's views above all the others'.

The role of a patient's will is illustrated well by a case that was heavily covered by the media at the time: that of Terri Schiavo, in the United States. In 1990, a medical incident caused this woman to enter a persistent vegetative state. She remained in that state for a little more than 15 years. Her husband believed that she would not have wanted to continue living in that state and argued for the removal of the tube that was being used to feed her and provide her with water. In contrast, Schiavo's parents hoped for their daughter's recovery – they favoured keeping her alive and were against the tube's removal. Schiavo did not have a patient's will, which would have revealed her intents in this respect. On account of the opposition from her parents, the tube kept the woman alive for 15 years.<sup>\*21</sup>

Under Estonian law, it would have been possible for such a situation to be catered for by expressing in a patient's will the intent to prohibit use of health-care services – use of a feeding tube. Since the use of a tube for food and water is a form of health-care provision, the physician does not have the obligation or the right to keep the patient alive with a tube unless the patient so wishes. In his or her actions, the physician who is aware of the patient's wish to discontinue with the health care service, has the right and obligation to discontinue using a tube of this sort even when its use has already begun.

<sup>19</sup> I. Bruus et al. Ravi ja hoolduse planeerimine nn patsienditestamendi koostamise teel ['Planning treatment and maintenance by preparing a patient's will']. – *Eesti Arst* 94 (2015) / 2 (in Estonian), p. 93; C. Westphal, T. Wavra. Acute and critical care choices guide to advance directives. American Association of Critical-Care Nurses 2005. Available online via <https://www.scribd.com/document/159374461/Acute-and-Critical-Care-Choices-to-Advance-Directives> (most recently accessed on 24.7.2017).

<sup>20</sup> K. Elmet. Eutanaasia. Arsti pilk ['Euthanasia: A doctor's perspective']. 2010. Available, in Estonian, at <http://www.eetika.ee/sites/default/files/eetika/files/Eutanaasia.%20Arsti%20pilk.pdf> (most recently accessed on 1.8.2018).

<sup>21</sup> A. Soosaar (see Note 1), pp. 218–219.

Schiavo was only 26 years old when she went into a persistent vegetative state. This illustrates that accidents may occur with young and healthy people; for example, they can unexpectedly be struck by illness or by a vehicle in a traffic accident. Therefore, although in practice the patient's will is particularly important for elderly and severely ill people, it can play a role in deciding over the lives of young and apparently healthy people too.

Unlike young and healthy people, older people and those who are seriously ill are more likely to perceive the ending of life more acutely. They are forced to think about what is going to happen to them, what kind of treatment they want, and in what state they want to continue to live. For doctors also, when treating severely ill patients, a question arises early about the patient's wishes related to further treatment, since they are aware of the possible outcomes. In such a case, it is in the interest of the attending physician to clarify the will of the patient when that person is still capable of making independent decisions. Otherwise, the expected will of the patient will have to be guessed at a later stage, in consultation with the family and others close to the patient – which, as explained above, can be a daunting task.

Although everybody may benefit from a patient's will, no-one should feel pressured to prepare one. No person is obliged to know in advance whether he or she wants to receive health care in the future when suffering from a difficult health condition. Everyone has the right to leave the burden of identifying his or her will to his or her loved ones as occurs, in accordance with the law, in the absence of a patient's will. Some people probably find that at such time as they become a patient incapable of making decisions, it would be more their loved ones who are concerned about their condition and further treatment, and they may conclude therefore that those loved ones should be given an opportunity to present the patient's expected will.

A question may arise as to whether a patient's will can be legitimately prepared by minors. According to the Declaration of Lisbon on the Rights of the Patient, a minor must be included in the decision to the extent that this is possible in his or her case.<sup>22</sup> If the opinion of a minor is meaningful in conditions wherein he or she can express it directly, his or her right to self-determination should be no less in a situation in which he or she no longer has the ability to express his or her will. However, in practice, it is not possible for a doctor to determine whether a minor who for reason of state of health is unable to express his or her will would be able to reasonably consider the pros and cons in the absence of health disorders. Therefore, a minor's patient's will may not be applicable in practice, and the health-care provider may take into account the decision of the legal representative of the minor and assess that decision in light of the patient's interests under §766 (4) of the LOA. Accordingly, the health-care provider must be guided by the interests of the minor patient.

Alongside bringing the benefits to the individual that are described above, the widespread use of patient's wills may have a wider impact on the distribution of health-care resources. In situations wherein patients who are incapable of exercising will do not want to receive treatment that prolongs life, their wishes expressed in a patient's will would enable redistribution of the resources for health care in a manner allowing their use by patients who do wish to receive treatment.

Although, for the reasons outlined above, what is to the patient's benefit can be beneficial both to the individual and to the health sector in general, the patient's will is, regrettably, not the solution to all situations. It has been compared with a seat belt, which alleviates some risks but does not guarantee prevention of undesirable consequences in all eventualities. The problems encountered in implementing the patient's will and their possible solutions are described in more detail in the sixth section of this article.

## 4. What to include in a patient's will

Although a person may have some idea of the situations he or she would like to avoid by means of a patient's will, expressing those wishes may seem complicated. The intent of each person and hence each patient's will is unique. Below, we will explain what to account for when compiling a patient's will and what we consider good to include in it.

A patient's will can be approached in any of various ways. For people who want to rule out prolonging their life through the provision of health care, the option most easily understandable by doctors and, hence, the most practicable approach would be to rule out the actions that the patient does not want to be

<sup>22</sup> WMA Declaration of Lisbon on the Rights of the Patient, p. 5. Available at <https://www.wma.net/policies-post/wma-declaration-of-lisbon-on-the-rights-of-the-patient/> (most recently accessed on 1.8.2018); J.R. Williams (see Note 2), p. 50.

performed. Thus, the patient's will could state what is desirable as a life-supporting treatment and what is not (e.g., resuscitation, artificial ventilation, dialysis, and/or a nutrition-providing probe).<sup>23</sup> In such a case, the person clearly expresses lack of consent to obtaining a specific form of health care within the meaning of §767 (1) of the LOA. Palliative (that is, pain-reducing) therapy should remain acceptable, in line with the goal under the patient's will's of reducing the patient's suffering. A sample of a patient's will based on this recommendation is included further on in this section of the paper.

In an alternative, it is possible to indicate in a patient's will the condition in which the person prefers to die. For example, it may be possible to exclude treatment that would result in the patient losing his or her limbs or render the patient blind. However, one must take into account that it is more difficult to implement such a solution. As a general rule, it is not clear what consequences the health-care provision might entail for the patient, except in cases such as those involving amputation. More importantly, the doctor does not know whether the patient is going to die in the absence of a particular health-care service or whether the patient is going to end up in a situation worse than what the patient wanted to achieve via the patient's will and accordant health care.

We will now explain which concrete steps should be taken to create a patient's will. Firstly, it should be made clear what the wishes of the person preparing the will are and the situations in which that person wishes his or her life not to be prolonged. Here, one must imagine the fullest possible range of situations that may arise. For example, one should think about what kind of health care would be desired after a traffic accident or in the event of illness (or exacerbation thereof) and consider what the consequences would be of health-care provision and of failure to provide health care. For this, one needs to consult a health-care professional. If the person preparing the will already has a serious illness, it is important to be aware of the prognosis and the disease's progression. Failure to take these into account could result in the patient's will being rendered useless because, most likely, the doctor will then have to decide about the treatment for the existing serious illness in the future. Although a patient's will may be drawn up without a health-care professional being consulted, this increases the likelihood that a large proportion of the probable situations are not going to be considered and that the patient's will instrument will not serve its purpose. An additional important step is for the intentions to be discussed with loved ones. Firstly, this helps people to figure out what they want, and, secondly, this consultation gives the loved ones knowledge of the patient's wishes. When the patient's will does not come as a surprise to the patient's loved ones later, there is a lower probability of them trying to interpret the will of the patient in a different manner.

When all possible situations and scenarios have been discussed with help from health-care professionals and relatives, correct wording needs to be found to express the person's wishes. In some countries, there are standard forms for a patient's will. These do make it easier to prepare from the patient's standpoint, but at the same time they do not provide flexibility, and they increase the risk of the true intentions not getting expressed. In Estonia, such standard forms are not used. The benefit of the patient's will and the chances of respecting the actual wishes of the patient are likely to be greater if the paper is prepared for the specific person concerned.

Just as finding out the person's wishes is important, so is doctors' assistance in compiling the patient's will. Although consultation on patient's wills has not been common practice for doctors in Estonia thus far, they are the ones who are most able to describe the procedures the patient wishes to avoid in the most accurate medical terms. However, it must be borne in mind that the patient's will is a document of legal significance whose formulation is new and unfamiliar to doctors. Therefore, it would be understandable if doctors wish to confine themselves to merely consultation that involves thinking through various scenarios and finding the correct medical terminology. In any case, legal assistance in preparing a patient's will is available by forwarding to the relevant legal practitioner one's wishes and a description of the possible scenarios and situations discussed with one's attending physician. It is advisable also for the person, after finalising of the patient's will, to discuss it again with his or her primary doctor to ensure that it is consistent with possible scenarios.

Another important consideration is that updating the patient's will may be necessary, given that both the wishes of the subject and the medical treatment options may change. Therefore, the patient's will should be

<sup>23</sup> I. Bruus et al. (see Note 19), p. 91; Communicate your health care wishes. California Advance Health Care Directive Kit. Permanente Medical Group, Kaiser Permanente 2005. Available at <https://shcs.ucdavis.edu/sites/default/files/documents/advance-directives-kp.pdf> ((most recently accessed on 24.7.2017)).

reviewed regularly (once a year or even more often), also in light of any disease prognosis and the treatment options. Ideally, the relevant doctor could check whether the patient has a patient's will in place whenever the prognosis and treatment options change and initiate discussion of whether the change in circumstances could lead to a change in the wishes expressed in the patient's will.

The following is a sample of a patient's will. The option presented rules out certain treatments that the patient does not want to receive. The model below is definitely not a standard form suitable for all people. Again, each patient's will is individual-specific, and the instrument must be prepared in accordance with the intent and health of the particular individual in question.

*EXPRESSION OF WILL IN RELATION TO PROVISION OF HEALTH-CARE SERVICES*

\_\_\_\_\_ day, month, year  
This declaration of intention has been made by \_\_\_\_\_, personal identification code \_\_\_\_\_.

*Pursuant to §766 (3) of the Law of Obligations Act, a patient may be examined and health care provided to him only with his consent. If the patient is unconscious or for any other reason is unable to express his will and does not have a legal representative, under §767 (1) of the Law of Obligations Act the provision of health-care services is permitted without the consent of the patient if their provision corresponds to his previously expressed will.*

*I hereby inform that, in a situation where I am not able to express my will, I allow only palliative care to be provided to me, for improvement of the quality of life of a patient who is facing a life-threatening illness and of the patient's family. The purpose of palliative care is to identify, assess, and treat pain and other physical symptoms of the disease and alleviate psychosocial and mental suffering as early as possible.*

*Because there is not a well-defined list of health care provided in the context of palliative care, I will specify that I do not give consent to any of the following:*

- *surgical treatment;*
- *resuscitation from clinical death;*
- *blood transfusion;*
- *mechanical ventilation, whether provided through intubation or via a hermetic mask;*
- *a probe or a tube inserted into the stomach through the stomach or into the venous system for administration of water and nutrients;*
- *kidney replacement treatment and kidney dialysis; and*
- *administration of drugs that have a purpose other than pain relief (such as antiviral or antibiotic therapy).*

*If the above-mentioned treatments or other non-palliative treatments are applied to me in a situation in which I have not been able to express my will (for example, in a situation wherein the health-care provider is not aware of this declaration of intention), I would like to see an immediate end to these therapies – i.e., the discontinuation of treatment that is against my intent.*

*I am aware that this declaration of intention will leave me without medical service that meets the general medical standard and may end with my premature death. I want to avoid hospitalisation if possible, and I want to die in my home.*

*For health-care professionals to be confident in respecting this declaration of intent, I have asked my notary to verify my active legal capacity and my capacity to exercise will, and I will proactively forward this document to the following health-care providers: [names of the health care providers to be inserted]. I have also made my wishes known to loved ones, and they have promised to respect these.*

## **5. How to establish a patient's will**

Estonian legislation does not imply that the patient's will should be in a certain form. Nor does Estonian legislation specify its validity. In contrast, in some countries there are certain procedural requirements in place for the patient's will, to protect the interests of both the maker and the implementer. A patient's will is an important – in fact, actually vital – document. Therefore, it must be taken into account too that the

patient's will, which determines the life of a person, may be falsified. Also, people may be compelled to sign the document under the pressure of a threat. In addition, someone may personally write a patient's will while having no capacity to exercise will and that is not in accordance with his or her actual intentions. In order to protect patients and give the health-care provider the necessary assurance, it is important to set formal requirements for the patient's will.

In consideration of the fact that there are no formal requirements for a patient's will in Estonia, we will present the formal requirements and related problems of patients in other countries.

Firstly, in the United States, nearly all states require at least two witnesses to be present when instructions for the future are being approved. Also, several states have strict guidelines in place as to who is qualified to witness at all.<sup>\*24</sup>

In France, the patient's will is to be documented in writing and must feature the date of its making and the signature of the maker.<sup>\*25</sup> Last year, the law introduced a model for a patient's will, allowing individuals to express their wishes. The existence of sample forms notwithstanding, the use of standard forms is not compulsory for the patient's will in France. If a person is able to declare his or her wishes but is unable to write and sign the document, witnesses must be involved. In this case, a third party may sign the document, provided that two witnesses certify that the document is a free and informed declaration of will by the maker of the patient's will. The testimony of witnesses must be attached to the patient's will, and the names of these witnesses and their legal capacity must be indicated. Since last year, patient's wills in France have been deemed entered into for an indefinite term, and they no longer need to be renewed, unless the maker wants to make changes.

Austria too has written requirements pertaining to binding patient's wills (the 'Patientsenförung'). In Austria, a binding patient's will must clearly indicate its date, and a lawyer, a notary, or a representative of the institute representing patients' interests must be present at its compilation. As a general rule, the document must be updated every five years.<sup>\*26</sup> A patient's will must be prepared in writing also in Germany.<sup>\*27</sup> Dutch legislation does not regulate patient's wills, but, in practice, notaries prepare them as notarial deeds and the general set of rules for a letter of authorisation has been taken as a basis, from the Civil Code<sup>\*28</sup>.

The foregoing discussion illustrates the fact that the patient's will's formal requirement fulfils two objectives. Firstly, the formal requirement reduces the risk that, instead of the subject named, someone else prepares the patient's will, doing so against the subject's intent. Secondly, the formal requirement reduces the risk of a person preparing a patient's will while in a condition in which he or she is unable to express his or her true intentions. The fact that a person formulates a patient's will in complete consciousness in line with his or her will is important, given that the patient's will is intended to protect the patient's personal autonomy. To hedge against the risks associated with the patient's will, it is advisable to impose a formal requirement in Estonia. In this connection, the notarial authentication requirement should be preferred, in consideration of the fact that it addresses both of these risks.

The purpose of involving a notary in drawing up a patient's will is to clearly, unambiguously, and definitively determine the content of the statement of intention. The role of a notary is to increase the rights and confidence of individuals in resolving legal issues, ensure the stability of relations between individuals, and thereby prevent legal disputes that are burdensome to the courts.<sup>\*29</sup> In this context, it would be necessary to clarify what the most important functions of notarial certification are. In its judgement of 28 January 2015, the Supreme Court highlighted several 'key functions embodied in the notarial deed of the transaction, stating:

<sup>24</sup> I. Bruus et al. (see Note 19), pp. 91–95; D. Hinders. Advance directives: Limitations to completion. – *The American Journal of Hospice & Palliative Care* 29 (2012) / 4, pp. 286–289. – DOI: <https://doi.org/10.1177/1049909111419293>.

<sup>25</sup> Code de la santé publique [The Public Health Code], Art. L1111-11. Available, in French, at [https://www.legifrance.gouv.fr/affichCode.do;jsessionid=BD10B9E5366ADCF78CFF5C7DBE1EA1E3.tplgfr22s\\_2?cidTexte=LEGITEXT000006072665&dateTexte=20180807](https://www.legifrance.gouv.fr/affichCode.do;jsessionid=BD10B9E5366ADCF78CFF5C7DBE1EA1E3.tplgfr22s_2?cidTexte=LEGITEXT000006072665&dateTexte=20180807) (most recently accessed on 7.8.2018).

<sup>26</sup> Patientenverfügungs-Gesetz – PatVG [The Living Will Act]. Available, in German, at [https://www.ris.bka.gv.at/Dokumente/BgblAuth/BGBLA\\_2006\\_I\\_55/BGBLA\\_2006\\_I\\_55.html](https://www.ris.bka.gv.at/Dokumente/BgblAuth/BGBLA_2006_I_55/BGBLA_2006_I_55.html) (most recently accessed on 1.8.2018).

<sup>27</sup> According to the first sentence of Section 1901 (1) of the German Civil Code (see the Bürgerliches Gesetzbuch, BGB).

<sup>28</sup> Dutch Civil Code, Book 3: Property law in general. Available at <http://www.dutchcivillaw.com/civilcodebook033.htm> (most recently accessed on 1.8.2018).

<sup>29</sup> E. Andresen. Notari koht ja roll Eesti õigussüsteemis [The place and role of a notary in the Estonian legal system]. – *Eesti Notariaadi X aastapäev*. Notarite Koda 2003 (in Estonian), p. 10.

- the notary shall elucidate the validity of the relevant facts for the performance of the current transaction, including the identity of the parties to the notarial act;
- the notary warns parties of the risks arising from the applicable law;
- the notary explains to the participants, impartially, ways to achieve the best result that corresponds to the intention of the transaction and the consequences of the transaction requested;
- the notary formulates a notarial deed containing the statement of intention and its explanations, ensuring that they are unambiguous;
- the content of the declaration of intention and the verified facts are verified by the notary as a competent official;
- the notary archives the original of the notarial deed in his office and allows access to it and obtaining copies of it<sup>30</sup>.

Thus, the purpose of a notarised authentication requirement for the declaration of intention can be a dual one: to protect both parties from ill-considered actions and to provide them with consultation. The notarised authentication requirement also serves as proof. Nowadays, inclusion of a notary is not justified in terms of taking evidence alone. A significantly more important task of verification is the warning or discretionary function in case of risky expressions of will.<sup>31</sup> A patient's will is undoubtedly one of the important transactions in this sense. Subjecting this to compulsory notarial authentication protects the person from 'rushing things' and supports careful consideration. Of all the formal requirements, notarial authentication is the one that best serves the function of warning. In the sense of legal certainty for the document, a notary's obligation to identify the subject (see §10 of the Notarisation Act) and to establish the subject's active legal capacity and capacity to exercise will (see §11 of the same act) is equally important.

On account of the above-mentioned factors, notarial formalisation of a patient's will should be preferred also in respect of the current laws, although the legislation currently foresees no such requirement. If the patient's will is not in a form that involves notarial assurances, health-care professionals do not truly dare rely on it, principally because they have no certainty that it is a will made by a particular person and that said person also was resolute in making that declaration.

## 6. Issues pertaining to implementation of a patient's will

Although a patient's will has an important role in relation to a person's right of self-determination and simplifying the life of the patient's loved ones, it may not always lead to expected outcomes.

As already mentioned, preparation of a patient's will is a relatively unknown process in Estonia. Therefore, the effective functioning of a particular patient's will may be hamstrung by the fact of the instrument, if it is compiled at all, having been prepared in a manner that does not enable its implementation or does not express the true will of the subject. Also, a person may disregard the fact that having a patient's will may leave him or her without medical care even in a situation wherein he or she would not incur any lasting harmful consequences or prolonged suffering after receiving medical care. With regard to expressing one's true will, mistakes may arise equally from the way in which consulting in preparation of a patient's will is handled. Research shows that people's desire to receive treatment depends, for example, on whether the outcomes of the treatment in question are presented in a positive or a negative manner, alongside how detailed the information is and whether short- or long-term effects are described.<sup>32</sup> For instance, in one study, with 201 elderly subjects, the participant requested medical intervention in 12% of cases when the intervention had been presented in a negative manner, in 18% of cases when it had been presented in terms of a guideline already in use, and in 30% of cases when the description had been phrased in a positive manner. Furthermore, 77% of the test subjects changed their mind at least once when presented with the same scenario but described differently.<sup>33</sup>

In order to reduce the risk that the patient's will does not represent the person's true will, several descriptions of the various scenarios should be used, to make sure that the person really intends to refuse

<sup>30</sup> RKTko 3-2-1-141-14, 28.1.2015, para. 32.

<sup>31</sup> W. Waldner. *Tõestamisõigus notariaalpraktikas* ['Notarisation Law in Notaries' Practice']. Juura 2008 (in Estonian), p. 19.

<sup>32</sup> A. Fagerlin, C.E. Schneider. *Enough: The Failure of the Living Will*. Hastings Center Report, March–April 2004, p. 33.

<sup>33</sup> B.B. Ott. *Advance Directives*, pp. 514, 517; *ibid.*, p. 33.

particular health-care services. Since consulting patients in preparation of patient's wills is unfamiliar territory for Estonian health-care workers, training on this subject should be organised. Such training is necessary also so that the health-care workers know how to check whether the patient has a patient's will and how to proceed in cases wherein one exists.

If a patient's will exists and contains the true, correctly expressed intentions of the patient, it could still be ignored, if its location is unknown and the health-care professional does not receive it in time. There are no mechanisms in place in Estonia addressing how to deliver information on the presence of a patient's will and its contents to health-care workers efficiently. This means that, for example, paramedics or doctors in an emergency room might provide health care to a patient and find out only later that there is a patient's will, according to which the patient never wished to receive such treatment. Also in intensive care, paternalism – that is, decision-making at the discretion of the doctor – often is inevitable because the physicians usually need to act rapidly and since frequently they possess no background information. Therefore, there is always a possibility of a refusal of treatment being ignored and a patient being hospitalised against his or her will and placed in intensive care.<sup>34</sup> Therefore, it should be taken into consideration that in situations wherein quick action is vital, doctors will not devote precious time to determining whether the patient may have a document somewhere that articulates a refusal of treatment.

For the patient's will to reach a health-care provider to whom it is targeted, the person should make the document as widely available to health-care providers as possible. To this end, the subject needs to send a notarially authenticated patient's will at least to the family doctor, the largest hospitals in the area, ambulance-service providers, and the E-Health Foundation. The patient definitely should request verification of receipt of the letter, of understanding its contents, and of taking it into account.

Such a solution is relatively inconvenient for both the person preparing the patient's will and its potential implementers. To make the use and implementation of a patient's will easier in the future, creating better-functioning technical solutions seems to be clearly in order. For example, one of the possibilities would be to create a register of patient's wills from which information is sent to health-care professionals automatically, via the e-health system, on whether a given patient has a patient's will and, if so, on the preferences that are expressed in that document.

## 7. Other considerations in preparing instructions for the future

When preparing instructions for their future, people need to think through the various decisions and protective measures related to maintenance of property and organisation of other matters in scenarios wherein a person has lost his or her capacity to exercise will.

In many countries, specific long-term letters of authorisation are used for organisation of matters associated with personal belongings and property, called lasting power of attorney (in German, *Vorsorgevollmacht*). These are prepared specifically against loss of capacity to exercise will. In practice, they may also contain instructions on how the person wishes to be treated medically. Use of lasting powers of attorney is especially widespread in the common law countries. Estonian law does not regulate powers of attorney of this nature. Authorisation agreements in general are regulated by Chapter 35 of the Law of Obligations Act and the institution of representation in §8 of the General Part of the Civil Code Act. Since a power of attorney is a transactional right of representation that can be tied to specific conditions, it could be claimed that Estonian legislation would enable preparation of a lasting power of attorney. In practice, however, such powers of attorney are not commonplace.

To give some examples of pertinent regulations in other countries, we can cite Finland, where a person at least 18 years of age may grant a power of attorney for a situation in which his or her situation has rendered him or her unable to take care of his or her monetary affairs. The power of attorney must be issued in writing, with the subject signing it in the presence of two witnesses. These witnesses must be aware that they have been invited to participate in providing a power of attorney, but they do not need to know the

<sup>34</sup> A. Lehtmets, K. Elmet. *Surmast arsti pilgu läbi* ['On death through the eyes of a doctor']. Viitna 2013. Available, in Estonian, at <http://www.etag.ee/wp-content/uploads/2012/05/Andres-Lehtmets.pdf> (most recently accessed on 1.8.2018).

contents of the document. Finally, for the power of attorney to enter into force, it must be verified by a guardianship authority (local register office).<sup>35</sup>

Lasting powers of attorney are known in Germany also. According to the second sentence of Paragraph 1896 (2) of the German Civil Code (BGB), guardianship is not required if the matters at issue for the adult can be taken care of by a person so authorised as well as by the guardian. German notaries use standards of regular powers of attorney in drawing up such documents, but lasting powers of attorney are supplemented: some additional characteristics are applied in accordance with the wishes and needs of the principal.<sup>36</sup> A provision similar to the relevant terms in German law can be found in the Estonian Family Law Act<sup>37</sup>, §203 (2) of which states that a guardian shall be appointed only for the performance of the functions for which guardianship is required. Guardianship is not required when the interests of an adult can be protected by granting of powers of attorney or by other measures. The version of the Family Law Act that entered into force in 2010 views imposing guardianship as an extreme intervention and sees appointing a guardian as a last resort. Hence, it should be the task mostly of notaries to develop a practical framework for lasting powers of attorney in Estonia.

## 8. Conclusions

One can state as a conclusion that there are hidden within Estonian law some currently unused measures that enable patients to exercise their right to self-determination, give peace of mind to their loved ones, and facilitate the work of health-care professionals in determining the will of a patient.

At the same time, the comparison between the patient's will instrument and a seat belt could be considered fitting: although a patient's will reduces the risks of receiving unwanted health-care services, it does not provide protection in every situation. To ensure nonetheless that a patient's will may bring the outcomes desired by the subject in as many situations as possible, the patient's will should be compiled in a well-weighed and correct manner. It should be taken into account also that so long as there remain no technical solutions for delivering the document to health-care providers, it is the person preparing the patient's will who needs to ensure that the document reaches as many health-care providers as possible who if unaware of it might provide unwanted health care to the patient.

In addition to a patient's will, other instructions for the future should be contemplated. In practice, it may be important for people to provide instructions on how their assets should be managed as a contingency against a situation wherein they have lost the capacity to express their will. Another tool that should be considered is adoption of lasting powers of attorney as are commonly employed in other countries.

<sup>35</sup> Laki edunvalvontavaltuutuksesta [The Act on Lasting Power of Attorney], §6. Available, in Finnish, at <http://www.finlex.fi/fi/laki/ajantasa/2007/20070648> (most recently accessed on 1.8.2018).

<sup>36</sup> C. Schall. Le portail des procurations préventives du C.N.U.E.: la voie vers un avenir plus autodéterminé en Europe [Title in English goes here]. – *Mobilité et Protection des Personnes Vulnérables en Europe: Connaissance et Reconnaissance des Instruments* [Title of Book in English Goes Here]. Société de Législation Comparée 2014 (in French), p. 50.

<sup>37</sup> RT I 2009, 60, 395; RT I, 9.5.2017, 28.