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Protecting human rights and dignity by taking into account previously expressed wishes of patients

Report[1]
Social, Health and Family Affairs Committee
Rapporteur: Mr Jordi XUCLÀ, Spain, Alliance of Liberals and Democrats for Europe

Summary

There is a general consensus, based on the European Convention on Human Rights and the Council of Europe Convention on Human Rights and Biomedicine,that a capable adult patient must not be manipulated and that his or her will, when clearly expressed, must prevail even if it signifies refusal of treatment: no-one can be compelled to undergo medical treatment against his or her will. If a patient is not, at the time of the intervention, in a state to express his or her wishes, they "shall be taken into account" if they had been previously expressed. These wishes can be formalised by advance directives, living wills or continuing powers of attorney.

All member states should put into place and implement legislation in this field to guarantee people's human rights and dignity, based on the Council of Europe acquis and on a set of principles outlined in this report. Council of Europe standards in this field should be developed further in accordance with these principles.

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[1] Reference to committee: Doc. 12088, Reference 3631 of 25 January 2010.

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A. Draft resolution[2]

1. There is a general consensus based on Article 8 of the European Convention on Human Rights (ETS No. 5) on the right to privacy that there can be no intervention affecting a person without his or her consent. From this human right flow the principles of personal autonomy and the principle of consent. These principles hold that a capable adult patient must not be manipulated and that his or her will, when clearly expressed, must prevail even if it signifies refusal of treatment: no-one can be compelled to undergo a medical treatment against his or her will.

2. The Council of Europe has included this principle in the Convention for the protection of human rights and dignity of the human being with regard to the application of biology and medicine: Convention on human rights and biomedicine(Oviedo Convention, ETS No. 164), which legally binds the majority of member states. The convention also covers the situation in which a patient is no longer able to express his or her will, by stipulating that the previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes “shall be taken into account”.

3. The ways in which these wishes can be formalised are advance directives, living wills or continuing powers of attorney. In Recommendation CM/Rec(2009)11 on principles concerning continuing powers of attorney and advance directives for incapacity, the Committee of Ministers recommended that member states promote these, and laid down a number of principles to guide member states in regulating them.

4. However, on the ground, the situation in Europe is very diverse, ranging from no legislation whatsoever on advance directives, to specific legislation which confers binding effect on them. Even where specific legislation does exist, it is not always fully implemented. Thus, today, only a tiny minority of the Council of Europe’s 800 million citizens actually have advance directives, living wills and/or continuing powers of attorney – making it difficult, if not impossible, to take their previously expressed wishes into account, and thus effectively protect their human rights and dignity.

5. The Parliamentary Assembly considers it essential that rapid progress be made in this area by member states to ensure that people’s human rights and dignity are guaranteed across the whole continent. It thus recommends that member states:

  5.1. sign, ratify and fully implement the Oviedo Convention, if they have not already done so;

  5.2. apply Committee of Ministers Recommendation CM/Rec(2009)11 on principles concerning continuing powers of attorney and advance directives for incapacity;

  5.3. review, if need be, their relevant legislation with a view to possibly improving it:

    5.3.1. for countries with no specific legislation on the matter – by putting into place a “road map” towards such legislation promoting advance directives, living wills and/or continuing powers of attorney, on the basis of the Oviedo Convention and Recommendation CM/Rec(2009)11, involving consultation of all stakeholders before the adoption of legislation in parliament, and foreseeing an information and awareness-raising campaign for the general public, as well as for the medical and legal professions after its adoption;

    5.3.2. for countries with specific legislation on the matter – by ensuring that the relevant Council of Europe standards are met by this legislation, and that the general public, as well as the medical and legal professions, are sufficiently aware of it and implement it in practice.

6. The Assembly, recalling its Recommendation 1418 (1999) on the protection of the human rights and dignity of the terminally ill and the dying, recommends that national parliaments, when legislating in this field, respect the following principles, in addition to those enshrined in the Oviedo Convention and Committee of Ministers Recommendation CM/Rec(2009)11:

  6.1. self-determination for capable adults in the event of their future incapacity, by means of advance directives, living wills and/or continuing powers of attorney, should be promoted and given priority over other measures of protection;

  6.2. advance directives, living wills and/or continuing powers of attorney should, in principle, be made in writing and be fully taken into account when properly validated and registered (ideally in state registries);

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[2] Draft resolution adopted unanimously by the committee on 4 October 2011.

6.3. prior instructions contained in advance directives and/or living wills which are against the law, or good practice, or those which do not correspond to the actual situation that the interested party anticipated at the time of signing the document, should not be applied;

6.4. advance directives, living wills and/or continuing powers of attorney should be accessible to all; thus, complicated forms or expensive formalities should be avoided;

6.5. capable adults should be encouraged to review at regular intervals (for example, once a year) the advance directives, living wills and/or continuing powers of attorney they have made, and should be able to revoke and/or change them at any time;

6.6. a system of supervision to fight abuse should be established under which a competent authority is empowered to investigate, and, if necessary, intervene, in particular in cases in which an attorney is not acting in accordance with the continuing power of attorney or in the interests of the granter.

B. Draft recommendation[3]

1. The Parliamentary Assembly, referring to its Resolution … (2012) on protecting human rights and dignity by taking into account previously expressed wishes of patients, commends the Committee of Ministers for its foresighted and timely adoption of both the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine(Oviedo Convention, ETS No. 164) and Recommendation CM/Rec(2009)11 on principles concerning continuing powers of attorney and advance directives for incapacity.

2. The Assembly believes it essential that rapid progress be made by member states in adhering to and implementing the standards enshrined in these texts. It thus recommends that the Committee of Ministers bring Parliamentary Assembly Resolution … (2012) to the attention of member states, with a request for implementation.

3. The Assembly further believes that Council of Europe standards in this field should be developed further. It thus recommends that the Committee of Ministers instruct its relevant steering committees (in particular, the Steering Committee on Bioethics), to continue developing such standards and to promote and monitor their implementation based on the principles enshrined in Committee of Ministers Recommendation CM/Rec(2009)11 and those developed in paragraph [6] of Assembly Resolution … (2012).

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[3] Draft recommendation adopted unanimously by the committee on 4 October 2011.

C. Explanatory memorandum by Mr Xuclà i Costa, rapporteur

1. Introduction

1. At the end of 2009, the then Chairperson of the Social, Health and Family Affairs Committee, Ms Christine McCafferty and 11 other parliamentarians tabled a motion for a resolution on living wills and the protection of human rights. This motion seeks to clarify whether a person has the right to decide whether to institute, continue or terminate medical treatment, and what might be the uses, benefits and limitations of living wills, with a view to better protecting health and human rights at all stages of life.

2. I was appointed rapporteur on this subject following its reference to the Social, Health and Family Committee for report in 2010. I presented an outline report to the committee in January 2011, which organised a hearing on the issue at its meeting in May 2011 with the participation of four experts.[4] Taking into account the opinion of the experts at the hearing, the committee agreed, on 16 September 2011, to my proposal to change the title in order to use the generic term of "previously expressed wishes"[5] of patients, whatever form they may take: living wills, advance directives, continuing powers of attorney, etc.

3. The Council of Europe is very active in the area of medical treatment in end-of-life situations. Several texts have already been adopted in this area (in chronological order):

– Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine(Oviedo Convention, ETS No. 164), 1997;

– Recommendation Rec(2003)24 of the Committee of Ministers on the organisation of palliative care;

– Recommendation CM/Rec(2009)11 of the Committee of Ministers on principles concerning continuing powers of attorney and advance directives for incapacity.

4. On 30 November and 1 December 2010, the Council of Europe Bioethics Division organised a symposium on the decision-making process regarding medical treatment in end-of-life situations, in which the Vice-Chairperson of the Committee, Mr Bernard Marquet, participated.

5. At the level of the Parliamentary Assembly, consensus on these matters has been less easy to reach. Although there have been several debates over the years (including on "Euthanasia" in 2003 and on "Assistance to patients at end of life" in 2005), only one resolution and one recommendation have been adopted by the Assembly in the last fifteen years:

– Recommendation 1418 (1999) on protection of the human rights and dignity of the terminally ill and the dying;

– Resolution 1649 (2009) on palliative care: a model for innovative health and social policies.

6. It is certainly not my intention to re-invent the wheel or re-open the euthanasia or assisted suicide debate. Instead, I would like to focus on how living wills, continuing powers of attorney and/or advance directives for incapacity can help answer the questions raised by Ms McCafferty and our colleagues in the motion for a resolution. I intend to structure my report in the following way: following an attempt at definitions and at outlining the general consensus on the principles underlying advance directives, I will present the existing international regulations (those put forward by the Council of Europe), before presenting the situation at national level, *inter alia* based on the presentations of Professor Andorno and Ms Erny at the hearing in Paris. I will then outline the main remaining challenges, finishing with my conclusions and recommendations.

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[4] For the programme, see document AS/Soc (2011) 21, for the minutes (which have been declassified), document AS/Soc (2011) PV 04 add rev. The participating experts were: Mr Roberto Andorno, Institute of Biomedical Ethics University of Zurich (Switzerland), Professor Andrii Butenko, Head of the International Scientific Relations Office of the National Academy of Medical Sciences, Kyiv (Ukraine), Ms Isabelle Erny, Head of the Rights, Ethics and Legal Support Division of the Ministry of Labour, Employment and Health (France), as well as representative of the Council of Europe Steering Committee on Bioethics (CDBI), and Professor Pablo Simón Lorda, Lecturer on Bioethics, Andalusian School of Public Health, Granada (Spain).

[5] This is, in fact, the term used in the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (Oviedo Convention, ETS No. 164).

2. Definitions

7. The concept of a “living will”, a “document of prior instructions” or an “advance directive” refers to a written document in which a capable person of legal age freely expresses in advance his or her will, so that it can be taken into account in situations in which the person can no longer express it him- or herself (for example, having lost legal capacity or consciousness). Advance directives (I will use this term from now on) can deal with the types of health care and treatment that the person would like to receive while he or she is alive (including in end-of-life situations) and also with the use of his or her body and organs once he or she is dead. Thus, the person can state if he or she wants to donate his or her organs and which ones, if he or she wants to be buried or incinerated and the type of ritual – religious or not – that he or she wants. In this report, I would like to focus on advance directives in the field of health care and treatment.[6]

8. The person who writes the advance directive can also designate a representative who he or she authorises to inform the doctors or the medical team of his or her will when the person is no longer able to do so (this is usually called a “continuing power of attorney”). This designation of a representative is important both to ensure the observance of the instructions of the person who has written the document and also to make new decisions that are not expressly stated in the document, to be made in accordance with the writer’s will and values. Therefore, the representative, relative or not, has to know the person who signs the advance directive very well, because he or she will act as a substitute in all the relevant medical decisions after being informed by the doctors.

3. Consensus on the principles

9. As I explained above, I find it very important to stress that we should not re-open a debate on those matters on which a general consensus has already been reached. This is why I would like to cite Ms Erny’s summary of the general consensus on the principles underlying advance directives at this point:

> *“On a legal plane, it is clear to all that advance directives have their foundations in the application of:*
>
> *– the principle of personal autonomy discerned by the European Court of Human Rights for the application of Article 8 of the European Convention on Human Rights on the right to privacy; there can be no intervention affecting the person without his or her consent;*
>
> *– the principle of primacy of the human being and more precisely the principle of consent enshrined in Articles 2 and 5 of the Convention on Biomedicine.*
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> *It follows from these principles that the patient must not be manipulated and that his or her will, when clearly expressed, must prevail even if it signifies refusal of treatment: no one can be compelled to undergo a medical treatment against his or her will. Consent, the principle that underpins the sector of patients’ rights and bioethics, is the prime expression of the principle of personal autonomy.*
>
> *Accordingly, in end-of-life situations, as long as a patient can express his or her will, he or she must be associated in the decisions that determine his or her treatment and the adaptation thereof; he or she may request its limitation or even cessation; no intervention and no treatment may be administered to him or her against his or her will, even if the prospect of survival is affected by desisting. The right to withdraw consent is indeed the corollary to the principle of giving consent.”*[7]

4. Regulations at Council of Europe level

10. On the basis of this general consensus, the Council of Europe has developed more concrete regulations.[8] I will briefly present their contents below.

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[6] Principle 14 of the Appendix to Committee of Ministers Recommendation CM/Rec(2009)11 on principles concerning continuing powers of attorney and advance directives for incapacity, however, explicitly stipulates a wider scope of application of advance directives: “Advance directives may apply to health, welfare and other personal matters, to economic and financial matters, and to the choice of a guardian, should one be appointed.” The World Health Organization defines advance directives as “a mechanism by which a competent individual expresses his or her wishes should circumstances arise in which he or she no longer is able to make rational and sound decisions regarding his or her medical treatment. Usually ‘advance directive’ refers to orders for withholding and/or withdrawing life support treatments at the end of life, made by writing living wills and/or granting power of attorney to another individual.” (Definition in 2004 glossary of terms, http://whqlibdoc.who.int/wkc/2004/WHO_WKC_Tech.Ser._04.2.pdf.)

[7] Document AS/Soc (2011) PV 04 add, minutes of the hearing on “Living wills and the protection of health and human rights”, held in Paris on 19 May 2011, p. 5.

11. The Oviedo Convention, the only legally binding text in this area to my knowledge which the majority of member states has ratified,[9] stipulates, in its Article 9 on “Previously expressed wishes” that:

> *“The previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account.”*

12. The convention’s explanatory report explains the article as follows:

> *“60. Whereas Article 8 obviates the need for consent in emergencies, this article is designed to cover cases where persons capable of understanding have previously expressed their consent (that is either assent or refusal) with regard to foreseeable situations where they would not be in a position to express an opinion about the intervention.*
>
> *61. The article therefore covers not only the emergencies referred to in Article 8 but also situations where individuals have foreseen that they might be unable to give their valid consent, for example in the event of a progressive disease such as senile dementia.*
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> *62. The article lays down that when persons have previously expressed their wishes, these shall be taken into account. Nevertheless, taking previously expressed wishes into account does not mean that they should necessarily be followed. For example, when the wishes were expressed a long time before the intervention and science has since progressed, there may be grounds for not heeding the patient's opinion. The practitioner should thus, as far as possible, be satisfied that the wishes of the patient apply to the present situation and are still valid, taking account in particular of technical progress in medicine.”*

13. As Ms Erny pointed out at the hearing, it becomes clear from this explanatory report that the authors of the convention did not wish to give the provision binding effect in all cases: “Wishes shall be 'taken into account' by the doctor who, though under an obligation to enquire about them, is only bound by them in so far as they are consistent with the present situation and with the patient’s interests. There is thus a margin of discretion in order that the instrument does not backfire on the patient and operates in a suitable and up-to-date manner. In the Convention on Biomedicine, “previously expressed wishes” are therefore an indicator of the patient’s will for the doctor which he cannot disregard, although he retains the possibility of reassessing the patient’s wishes in the light of the actual situation that presents itself, and of advances in medicine especially. The Article 9 provision, however, raises no impediment to state arrangements for regular living wills with binding effect.”[10]

14. The Committee of Ministers has subsequently gone further than the authors of the convention and has laid down guidelines on continuing powers of attorney and advance directives for incapacity in its Recommendation CM/Rec(2009)11. The key recommendation contained therein is that governments of member states “promote self-determination for capable adults by introducing legislation on continuing powers of attorney and advance directives or by amending existing legislation with a view to implementing the principles contained in the appendix to this recommendation”.

15. In the appendix to the recommendation, the Committee of Ministers has formulated a number of principles which cover the content, form, and appointment/termination of attorney (and his or her role and supervision), as well as the content, form, effect and revocation of advance directives. I think that the following are the most important, which is why I would like to highlight them here.

Concerning the scope of application

– Principle 1: “1. States should promote self-determination for capable adults in the event of their future incapacity, by means of continuing powers of attorney and advance directives. 2. In accordance with the principles of self-determination and subsidiarity, states should consider giving those methods priority over other measures of protection.”

Concerning continuing powers of attorney

– Principle 8: “States should consider introducing systems of certification, registration and/or notification when the continuing power of attorney is granted, revoked, enters into force or terminates.”

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[8] I am not aware of any other international and/or European regulations which are applicable in the majority of the Council of Europe’s member states.

[9] Currently in force in 28 states (with a further seven signatures not followed by ratification).

[10] Minutes of the hearing, op. cit., p. 6.

- Principle 12: “1. The granter may appoint a third party to supervise the attorney. 2. States should consider introducing a system of supervision under which a competent authority is empowered to investigate. When an attorney is not acting in accordance with the continuing power of attorney or in the interests of the granter, the competent authority should have the power to intervene. …”

Concerning advance directives

- Principle 15: “1. States should decide to what extent advance directives should have binding effect. Advance directives which do not have binding effect should be treated as statements of wishes to be given due respect. 2. States should address the issue of situations that arise in the event of a substantial change in circumstances.”
- Principle 16: “1. States should consider whether advance directives or certain types of advance directives should be made or recorded in writing if intended to have binding effect. 2. States should consider what other provisions and mechanisms may be required to ensure the validity and effectiveness of those advance directives.”
- Principle 17: “An advance directive shall be revocable at any time and without any formalities.”

16. The Assembly, for its part, communicated its recommendations to the Committee of Ministers in 1999, in Recommendation 1418 (1999) on protection of the human rights and dignity of the terminally ill and the dying, including their “right to self-determination” (see paragraph 9). The Assembly asked the Committee of Ministers to encourage the member states of the Council of Europe to:

- “ensure that, unless the patient chooses otherwise, a terminally ill or dying person will receive adequate pain relief and palliative care, even if this treatment as a side-effect may contribute to the shortening of the individual’s life;
- to give effect to a terminally ill or dying person’s right to truthful and comprehensive, yet compassionately delivered information on his or her health condition while respecting an individual’s wish not to be informed;
- to ensure that no terminally ill or dying person is treated against his or her will while ensuring that he or she is neither influenced nor pressured by another person. Furthermore, safeguards are to be envisaged to ensure that their wishes are not formed under economic pressure;
- to ensure that a currently incapacitated terminally ill or dying person’s advance directive or living will refusing specific medical treatments is observed. Furthermore, to ensure that criteria of validity as to the scope of instructions given in advance, as well as the nomination of proxies and the extent of their authority are defined; and to ensure that surrogate decisions by proxies based on advance personal statements of will or assumptions of will are only to be taken if the will of the person concerned has not been expressed directly in the situation or if there is no recognisable will. In this context, there must always be a clear connection to statements that were made by the person in question close in time to the decision-making situation, more precisely at the time when he or she is dying, and in an appropriate situation without exertion of pressure or mental disability. To ensure that surrogate decisions that rely on general value judgements present in society should not be admissible and that, in case of doubt, the decision must always be for life and the prolongation of life;
- to ensure that – notwithstanding the physician’s ultimate therapeutic responsibility – the expressed wishes of a terminally ill or dying person with regard to particular forms of treatment are taken into account, provided they do not violate human dignity;
- to ensure that in situations where an advance directive or living will does not exist, the patient’s right to life is not infringed upon. A catalogue of treatments which under no condition may be withheld or withdrawn is to be defined.”

17. Ten years later, the Assembly, in its Resolution 1649 (2009) on palliative care: a model for innovative health and social policies, “recognises that the limits of any medical intervention are determined by the autonomy of the individual patients in so far as they express their will not to receive curative treatment or, regardless of any medical assessment of their state of health, have done so explicitly in a living will, for instance”.[11] With regard to legal regulations on living wills, the Assembly recommended “avoid[ing] creating legal arrangements which could lead to interpretation problems in practice” and “conduct[ing] a comprehensive assessment of the legal consequences, taking account of possible legal side effects such as asset liability ('care as a financial loss')”.[12]

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[11] Paragraph 12 of the resolution.

5. Regulations at national level: overview and the case of Spain

5.1. Overview

18. According to Professor Andorno, the situation in Europe is very diverse, ranging from no legislation whatsoever on advance directives, to specific legislation which confers binding effect on them. Professor Andorno distinguishes four groups of countries (categories followed by selected examples):

- "countries where specific laws have been adopted making advance directives legally binding (Austria, Belgium, Finland, Germany, Hungary, the Netherlands, Spain, Switzerland, United Kingdom);
- countries where specific laws on this matter have been adopted in recent years, though these documents are not legally binding (France);
- countries where there is no specific legislation yet, but which are planning to introduce it in the next few years (Italy);
- countries where there is no specific legislation yet and which do not have concrete plans to introduce it in coming years (Bulgaria, Greece, Lithuania, Norway, Portugal, Serbia, Slovakia, Turkey)."[13]

19. Even in countries which have adopted specific laws making advance directives legally binding, the exact laws and specifications differ, as does the degree of their actual implementation. This could be due to culture – Professor Andorno noted that national approaches varied according to the degree of patient autonomy, which was given prominent value in some countries whilst others relied on more "paternalistic" decision-making structures.[14] But it could also be due to the different standards of care in member states connected with their different standards of living – Professor Butenko pointed out, for example, that national laws concerning living wills did not exist in Ukraine for the time being, mainly because the level of interest in the issue was generally very low as a majority of people were mostly preoccupied with access to basic services in the context of the current deficient health-care system in the country.[15]

5.2. Spain

20. As I know the Spanish regulations in the field very well, I would like to present them here as an example of "good practice" (which can nevertheless, of course, still be improved upon). The laws that regulate living wills in Spain affirm that prior instructions which are against the law, are not good practice or those which do not correspond to the actual facts that the interested party anticipated at the time of signing the document will not be applied. This is a provision, to my knowledge, which is found in all laws of countries which have made advance directives legally binding.[16]

21. Concerning these limits, it is important to say that even if at the time of signing the living will some practices are not available or are illegal, they can become available or legal in the future. Consequently, the person who signs a living will can include desires and demands which are impossible to have applied at that moment but which could possibly be fulfilled in the future.

22. For the living will to be accessible to all the medical community, it is mandatory to register it in a national register and to include it in the clinical history of the person who signed it. Moreover, a living will can always be revoked by the person who signed it, under the same conditions as when he or she signed it.

23. In Spain, a living will can be formalised in three ways:

a. Before a notary. In this case, the presence of witnesses is not needed.

b. Before three witnesses of legal age and with full legal capacity. Among these three witnesses, at least two of them cannot be relatives (up to and including cousins) and cannot have any patrimonial relationship with the interested party.

c. Before a government civil servant (normally an employee of the Living Will Registry of the Autonomous Region). In this case, the presence of witnesses is also not needed.

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[12] Paragraph 22.5 of the resolution.

[13] Minutes of the hearing, op. cit., p. 2.

[14] Ibid., p. 3.

[15] Ibid.

[16] This provision is a safeguard against illegal acts – thus, for example, a request for euthanasia in a country where it is illegal will not be given effect.

24. The direct participation of health professionals is not required in Spain.[17]

6. Remaining challenges

25. A recent bulletin of the World Health Organization's (WHO) regional office for Europe[18] on palliative care for older people explains that "older people may benefit from making advance statements, including reducing the burden of decision-making on their families, but they also have concerns about associations with euthanasia; the possibility that preferences for care may change; reluctance to think about death; and the time needed for older people to trust professionals enough to talk about such sensitive issues. There are also concerns that such statements are nearly always about treatment withdrawal rather than specifying active choices, with the fear that this feeds into prejudice against age and disability. Some doctors are unsure of the legal status of advance directives, which can result in them being misapplied or ignored".

26. I think this is quite a good summary of the remaining challenges to be faced. I would like to go through the implications one by one:

6.1. Promotion of advance directives

27. Advance directives, whatever form they take (living wills, continuing powers of attorney, etc), are to the benefit of everyone involved, from the patient (who can thus ensure that his or her previously expressed wishes are taken into account), over the relatives (whose decision-making burden in highly emotional circumstances is reduced) to the doctor (who can tailor treatment and care to the patient's previously expressed wishes). It is thus not just "older people" who should make advance directives – everyone should. Indeed, this is the official position of the Council of Europe, which in Committee of Ministers Recommendation CM/Rec(2009)11 recommended that states promote continuing powers of attorney and advance directives and should consider giving those methods priority over other measures of protection, in accordance with the principles of self-determination and subsidiarity.

6.2. Associations with euthanasia and concerns about treatment withdrawal

28. The associations with euthanasia are unfortunate, and – in most countries (the vast majority of Council of Europe member states outlaw euthanasia) – wrong. Making an advance directive can, on the contrary, help to ensure that no form of euthanasia is practised on oneself against one's will: an advance directive can also legitimately state: "I do not want anything done or omitted by my doctors or nurses with the intention of taking my life."[19] Similarly, advance directives are not slanted towards treatment withdrawal versus "active choices"; an advance directive can state the patient's preference for life-support treatment (and which kind of treatment) in different circumstances, in the same way as that preference can be conditional (e.g. accepted on the premise that it might help the condition) or refused. What is needed is a more open debate on end-of-life situations in general and a more informed debate on advance directives in both the body politic and the general public in order to dispel the wrong associations with euthanasia.

6.3. Taking into account changes in the preferences for care

29. It is important that legislation on advance directives foresees the possibility for a person's/patient's preferences to evolve over time, and thus make it possible to change the advance directives (provided that the patient remains capable of decision making[20]). Indeed, this is the official position of the Council of Europe, which in Committee of Ministers Recommendation CM/Rec(2009)11 stated the principle that: "An advance directive shall be revocable at any time and without any formalities."[21] In fact, everyone who makes an advance directive should be encouraged to review that directive at regular intervals, for example once a year.[22]

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[17] This detachment of advance directives from a clinical context, where decisions in end-of-life situations are normally taken, constitutes a serious problem in the view of Professor Lorda. See minutes of the hearing, op. cit., p. 1.

[18] WHO Regional Office for Europe: Palliative care for older people: better practices, 2011, www.euro.who.int/__data/assets/pdf_file/0017/143153/e95052.pdf.

[19] A proposal made in an American version of an advance directive and continuing power of attorney, called "Five wishes", Wish 2. See the website of the NGO "Aging with dignity": www.agingwithdignity.org/five-wishes.php.

[20] This is problematic in the case of old-age dementia, for example.

[21] Principle 17.

[22] This is the recommendation of Germany's Federal Ministry of Justice, for example.

6.4. Trust in professionals, legal status and proper application of advance directives

30. In a patriarchal and/or paternalistic culture where “doctor knows best”, patients – women in particular – are sometimes not even told by their doctor or their family that they have a terminal disease. It is a big jump from this type of culture to a mindset which empowers the patient to make active choices about their treatment and care when they are unconscious or unable to express their wishes. But full and informed consent to medical treatment is a precondition for that treatment not to be a human rights violation, and culture should not be allowed to stand in the way of human rights. That is why it is important that all Council of Europe member states which do not yet regulate advance directives establish a road map to them, as Professor Butenko suggested during the hearing.[23]

31. It is equally important that both health and other professionals (for example in the legal profession, or civil servants) involved in giving advice on advance directives be properly trained to do so adequately. Similarly, those professionals asked to apply the directives should be well informed about their legal status and their proper application. Ideally, advance directives enable previously expressed wishes of patients to be fully taken into account in a dialogue with carers and family members: for this, trust in the professionals needs to be established.

6.5. Making advance directives understandable and accessible

32. One aspect not mentioned by WHO, but which I personally find central, is the challenge of making advance directives “understandable” and accessible. In the United States of America, the percentage of people with advance directives is far higher than in European countries – this may be both a matter of culture and linked to the standard of care, but it may also be linked to the fact that one form developed by a non-governmental organisation seems to dominate (“Five wishes”). This form (which costs US$5) is available in many languages and types, can be filled in online or in print form, and is written in a language which is easy to understand, making it accessible to most. It may not have the legal sophistication of the model put forward by the German Federal Ministry of Justice, for example, but I personally think that the multiplication of complicated model forms to choose from (as in Spain, where there are several different forms in the 17 autonomous regions) discourages rather than encourages people from making advance directives, as do too high fees connected with setting them up.

33. Once an advance directive has been made, it is important that it can be consulted immediately when needed. The question of where such directives should be registered is thus also one of accessibility: personally, I quite like the Spanish model of public regional registries – which could (and perhaps should) be complemented by a national registry.

7. Conclusions and recommendations

34. There is a general consensus based on Article 8 of the European Convention on Human Rights on the right to privacy that there can be no intervention affecting the person without his or her consent. From this human right flow the principles of personal autonomy and the principle of consent. These principles hold that the patient must not be manipulated and that his or her will, when clearly expressed, must prevail even if it signifies refusal of treatment: no one can be compelled to undergo a medical treatment against his or her will.

35. The Council of Europe has included this principle in the Oviedo Convention, which legally binds the majority of member states. The convention also takes into account the situation in which a patient is no longer able to express his or her will by stipulating that the previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes “shall be taken into account”. The ways in which these wishes can be formalised are advance directives, living wills or continuing powers of attorney. In 2009, the Committee of Ministers recommended that member states promote these, and laid down a number of principles to guide member states in regulating them.

36. However, on the ground, the situation in Europe is very diverse, ranging from no legislation whatsoever on advance directives, to specific legislation which confers binding effect on them. Even where specific legislation does exist, it is not always fully implemented, and the take-up of advance directives, living wills and/or continuing powers of attorney mostly remains low.

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[23] Minutes of the hearing, op. cit., p. 3.

37. I consider that the Council of Europe has done the right thing by promoting these tools, which make it possible to protect human rights and dignity by taking into account previously expressed wishes of patients. However, further promotion is obviously needed: more countries need to ratify the Oviedo Convention, more countries need to apply Recommendation CM/Rec(2009)11, and all countries need to review their relevant legislation with a view to possibly improving it. This is where I hope the Parliamentary Assembly will be able to make a substantive contribution.