



COMPETENCE ASSESSMENT AND ADVANCE DIRECTIVES FOR PEOPLE WITH DEMENTIA: ETHICAL AND LEGAL ASPECTS

COLOPHON

Rights, autonomy and dignity of people with dementia

Can competence assessment and advance directives help to find the right balance between autonomy and protection?

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I. Foreword

Healthy life expectancy has dramatically increased in Europe over the past 50 years. At the same time, there has been a corresponding increase in diseases linked to aging, particularly dementia. Alzheimer's disease and related dementias are an EU public health priority given their high prevalence and cost as well as the profound impact they have on society.

This publication is made in the framework of the European Joint action ALCOVE (Alzheimer Cooperative valuation in Europe). Over two years (from April 2011 to April 2013) Alcove has built a sustainable network which includes 30 partners from 19 EU Member States. Through its work, ALCOVE has aimed to improve knowledge and to promote the exchange of information on dementia in order to preserve the health, quality of life, autonomy, and dignity of people living with dementia and their carers in EU Member States.

This report is the result of the work done by one of the Alcove workpackages on rights, autonomy and dignity of people with dementia (Literature research, consultations and workshops)

Working on ethics at European level is a challenge due to differences in moral, ethnic, cultural and religious commitments. However during the ALCOVE project we easily identified some values common that are largely shared in the EU:

- *The dignity and identity of all human beings need to be protected, regardless of their medical condition. In the case of dementia, we are forced to explore the dignity, decision-making competence and civic rights of the individual in new terms.*
- *Autonomy is an essential value in medical ethics. The respect given to a person's rights, choices and preferences is crucial. Dementia raises difficult ethical issues because the person's competence (and by extension competence to consent) is changing and evolving continuously.*

During different international interdisciplinary workshops we succeeded to build further on these common values and tried to find ways to put these values into practice. We explored two tools : competence assessment to respect the remaining capacities of the person with dementia and advance directives to respect the wishes and preferences of the person with dementia.

We did not give an answer to all questions related to this but we hope this work will help as well persons with dementia and their family, as professional cares and decision makers to have a more balanced view of dementia and to respect each person's autonomy. This will certainly go towards an improvement to the quality of life of people with dementia and those around them.

The King Baudouin Foundation was designated the Minister of Health to contribute to this Joint Action¹

We wish to thank Prof. Herman Nys for the scientific coordination and the two partners of this workpackage Terveiden Ja Hyvinvoinnin Laitos) (THL), Finland and Assistance Public -Hôpitaux de Paris, Espace Ethique (EEAPHP), France.

More information on Alcove : <http://www.alcove-project.eu/>

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We thank particularly all participants to the different interdisciplinary workshops for their contribution to the reflexion and to the formulation of the ALCOVE recommendations. (list of participants)

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II. INTRODUCTION

The dignity and identity of all human beings need to be protected, regardless of their medical condition. In the case of dementia, we are forced to explore the dignity, decision-making competence and civic rights of the individual in new terms.

Autonomy is an essential value in medical ethics. The respect given to a person's rights, choices and preferences is crucial. Dementia raises difficult ethical issues because the person's competence (and by extension competence to consent) is changing and evolving continuously.

From an ethical perspective it is crucial to strike the right balance between the autonomy of the person living with dementia and the protection of this person and his or her environment. The availability of high quality care and legal provisions is a prerequisite for the respect of a person's dignity. But striking the right balance is not only a question of care models or laws, but also, and more importantly, one of listening and understanding. In order to take into account the diversity of personal wishes, social values, and cultural backgrounds; as well as the fluctuating cognitive and functional competences resulting from the disease, a permanent dialogue between the person living with dementia and his or her formal and informal caregivers is needed.

Competence assessment tools and advance directives have been suggested as tools to foster and support dialogue between persons living with dementia and their environment.

We have explored how on one hand the assessment of competence and on the other hand the drawing up and use of advance directives by persons living with dementia can help these persons to strengthen their rights and have their autonomy respected while protecting them and their environment at the same time.

Three specific tasks were undertaken:

- **A critical review** of the medico-legal (KU Leuven, Belgium) and bioethical (Espace Ethique, Assistance Public-Hôpitaux de Paris, France) literature regarding the concept and assessment of competence and the international and national regulation of advance directives.
- **A questionnaire survey** regarding the legal regulation of advance directives in EU Member States.
- **3 workshops:**
 - International workshop 1: Finding the right balance between autonomy and protection of the person with dementia. Advance directives and competence assessment
 - Workshop 2: Antipsychotics and Alzheimer-like diseases
 - International workshop 3: Finding the right balance between autonomy and protection of the person with dementia. Advance directives and competence assessment: discussion of the draft-recommendations

III. COMPETENCE ASSESSMENT

1. Key messages

Competence & Dementia

- *Presumption of competence.*
- *Distinction between decision-making capacity (in a care and treatment context) and functional competence. Functional competence relates to the ability to perform activities of daily life, live alone, drive a car, etc.*
- *Respect of the person's remaining capacities.*

The presumption of competence: The term competence cannot easily be defined. It is a multidimensional construct with important clinical, legal, ethical, social, and policy aspects. Competence in a care and treatment setting refers to 'decision making capacity' or 'capacity for autonomy'. This decision-making capacity in a care and treatment setting is not linked to performing acts with legal consequences – as competence does in a juridical framework - but refers to a more personal context. It is linked to making choices regarding the integrity of the individual him/herself, restricted to a specific (medical) care intervention, and this competence is usually assessed by a medical professional and not a judge.

One must also make the distinction between decision-making capacity (in a care and treatment context) and functional competence or functional capacity. Functional competence relates to the ability to perform activities of daily life, live alone, drive a car, etc.


For a person to be competent, (s)he should be able to understand a task or a situation, appreciate the relevance, the emotional impact, the rational requirements or the future consequences of a decision. (S)he should be able to reason on the risks and benefits and weigh the arguments, and finally (s)he should be able to express a choice. This implies that competence varies with regard to the purpose under consideration. It also depends on various aspects of personality, affective regulation, and intellectual or cognitive functioning of the person. In addition, somatic factors play a role: visual and hearing functioning, as well as the influence of substances or drugs might influence competence and its assessment.

Because of the important impact of the disease on daily life, a person living with dementia is almost always confronted with a presumption of incompetence. Before the person has even spoken, his or her words are marked by a systematic devaluation² of his or her capacities. The opposite approach should be promoted. The person living with dementia should be "presumed capable": "still capable of" rather than "now incapable of"³. Incapacity is not to be deduced automatically from a diagnosis of dementia.

A protective attitude, inspired by the "precautionary principle" is too often privileged when coping with the alteration and the progressive loss of decision-making capacities of a person with dementia. But this attitude can threaten a person's capacity of taking initiatives and his or her feeling of control over his or her own life, whether (s)he is staying at home or living in an institution. Under certain circumstances, giving up specific activities (when the disease is at an advanced stage) can be justified

² National authorities are encouraged to provide a legal framework on advance directives adapted to the specific needs of persons living with dementia

³ Proper models and good practices specifically oriented towards people living with dementia need to be implemented, further developed and disseminated, because all stakeholders – patients, relatives, informal and formal carers, healthcare policy organisations, ... – have to be made aware of the specificities and complexities regarding advance care planning and advanced directives for people living with dementia



by the best interest of the person and his or her surroundings (driving a vehicle, manipulating dangerous objects), but it is doubtful whether systematic decisions of this kind are respectful of the person's autonomy and take into account his or her remaining capacities. The specific context in which these decisions are taken should always be examined thoroughly and re-evaluated regularly. Numerous tools to assess competence have been developed⁴, but many have not been validated or are not task-specific. Assessment of competence should be used to enhance the welfare of people with dementia. It should serve to provide help and shelter to those whose competence is reduced and autonomy to those whose competence is maintained.⁵

2. Some legal and ethical aspects of competence assessment

2.1 Terminology

This report uses the expression 'competence assessment' because this term is commonly accepted in health care. However we prefer to speak of 'capacity' instead of 'competence' when this term is not used together with assessment. The English term most used is indeed 'capable to/of' or 'capacity'.⁶ This is in accordance with the recommendation R (2009) 11 on principles concerning continuing powers of attorney and advance directives for incapacity. According to § 39 of the Explanatory Memorandum this Recommendation distinguishes between 'capacity' and 'legal capacity' while the terms 'capacity' and 'capable' are the counterparts of 'incapacity' and 'incapable'. 'Incapacity' is limited to what might be termed 'factual incapacity', or in some states 'mental incapacity', although the latter term is outdated and unpopular. Such (factual) incapacity may impair the ability of an adult to make decisions, assert and exercise rights, and so forth. An extreme form is the incapacity of a person in a coma or in persistent vegetative state. Although severe dementia or a profound learning disability (formerly 'mental handicap') can cause substantial incapacity, many other conditions can cause various lesser degrees of incapacity. It is, however, fundamental that such factual or mental incapacity, here termed 'incapacity', never detracts from the adult's rights and status in law. In other words, (factual) incapacity does not automatically lead to legal incapacity. Legal incapacity results from a formal decision made by a judge after medical expertise.

While in the past 'capacity' and 'legal capacity' have often been used synonymously, a trend has emerged of using 'legal capacity' to encompass the adult's rights and status themselves, rather than the ability to exercise and assert them. Under that usage, 'legal incapacity' refers to the diminution by law of an adult's rights and status. Persons with disabilities should never have such legal incapacity imposed upon them by reason of their disabilities. This point is stressed by the 2006 United Nations Convention on the Rights of Persons with Disabilities, which uses 'legal capacity' in that sense. Article 12.2 of that Convention provides: 'States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.' The Recommendation (2009) 11 uses 'legal incapacity' in that same sense.⁷

⁴ The person's current attitude towards a certain treatment or a care intervention - ascertained feelings, desires and wishes - should always be taken into account, even if there is an advance directive or a designated proxy, since there can be major changes in values and preferences between the time when persons complete their advance directive and when it comes into effect

⁵ Although the use of advance directives should be promoted, nobody can be forced to make up an advance directive. If a person does not want to address issues about future care and treatment or end-of-life for his- or herself, this needs to be respected.

⁶ H-W. Am Zehnhof a.o., *Legal dictionary in four languages*, Antwerp, Intersentia, 2011,89: capable to contract; to marry; of giving and receiving gifts; of disposing of his chattels; of instituting legal transactions; of inhering; capacity to contract; to appear in court; civil capacity; testamentary capacity; special capacity; competence to administer; certificate of competence.

⁷ Explanatory memorandum to Rec (2009)11, § 40.

2.2 The European Convention on Human Rights

The European Convention on Human Rights (ECHR) (formally the *Convention for the Protection of Human Rights and Fundamental Freedoms*) is an international treaty to protect human rights and fundamental freedoms in Europe. Drafted in 1950 by the then newly formed Council of Europe, the Convention entered into force on 3 September 1953. All Council of Europe member states and thus by definition all EU member states are party to the Convention. The Convention established the European Court of Human Rights (ECtHR). Any person who feels his rights have been violated under the Convention by a state party can take a case to the Court. The European Convention is still the only international human rights agreement providing such a high degree of individual protection.

The ECHR does not contain a provision regarding competence assessment and (legal) incapacity but nevertheless the Convention is more than relevant to this issue because of article 8 which provides:

- '1 Everyone has the right to respect for his private and family life, his home and his correspondence*
- 2 There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.'*

The importance of a well-balanced and 'tailor-made' competence assessment has been highlighted by the European Court of Human Rights in different cases namely *Shtukaturv vs. Russia* of 27 March 2008 and more recently *Sykora vs. Czech Republic* of 22 November 2012.⁸ In *Shtukaturv* the applicant alleged that by depriving him of his legal capacity without his participation and knowledge the domestic courts had breached his rights under (among others) article 8 of the Convention. In the Court's opinion the existence of a mental disorder, even a serious one (in this case schizophrenia) cannot be the sole reason to justify full incapacity. In order to justify full incapacity the mental disorder must be "of a kind or degree" warranting such a measure. The Russian Civil Code distinguishes between full capacity and full incapacity, but it does not provide for any "borderline" situation other than for drug or alcohol addicts. The Court referred in this respect to the principles formulated by Recommendation R (99) 4 of the Committee of Ministers of the Council of Europe (see below). Although these principles have no force of law for the Court, they may define a common European standard in this area⁹. Contrary to these principles, Russian legislation did not provide for a 'tailor-made response'. As a result, in the circumstances the applicant's rights under Article 8 were limited more than strictly necessary. In the *Sykora* case the Court recognized that in such a complex matter as determining somebody's mental capacity the authorities should enjoy a wide margin of appreciation. This is mostly explained by the fact that the national authorities have the benefit of direct contact with those concerned, and are therefore particularly well placed to determine such issues. However, whilst article 8 of the Convention contains no explicit procedural requirements, the decision-making process involved in measures of interference must be fair and such as to ensure due respect of the interests safeguarded by article 8. The extent of the State's margin of appreciation thus depends on the quality of the decision-making process. If the procedure was seriously deficient in some respect, the conclusions of the domestic authorities are more open to criticism (see *Shtukaturv*, § 87-89). Any deprivation or limitation of legal capacity must be based on sufficiently reliable and conclusive evidence. An expert medical report should explain what kind of actions the applicant is unable to understand or control and what the consequences of his illness are for his

⁸ Hudoc.echr.coe.int.

⁹ See also W.Pintens, 'A new Recommendation on continuing powers of attorney' in A.Büchler and M.Müller-Chen, *Private law, national-global-comparative.Festschrift für Ingeborg Schwenzer zum 60.Geburtstag*, Bern, Stämpfli,2011,1413.

social life, health, pecuniary interests, and so on. The degree of the applicant's incapacity should be addressed in sufficient detail by the medical reports (see Shtukaturov, §§ 93-94). These judgments relate to legal incapacity. They are also relevant for the assessment of factual capacity because this also requires what the Court has called a 'tailor-made' approach.

2.3 European Convention on Human Rights and Biomedicine

The Convention on Human Rights and Biomedicine (hereafter: the Biomedicine Convention) was adopted by the Committee of Ministers of the Council of Europe on 19 November 1996 and opened for signature in Oviedo, Spain on 4 April 1997. After the fifth ratification, that of Spain, the Convention entered into force on 1 December 1999. As of this moment 29 (of 46) Member States of the Council of Europe have ratified the Convention. The Convention consists of a preamble and 28 articles, organized into 14 chapters. The general norms are contained in chapter I, which consists of articles 1 to 4; chapters II to VII set up substantive provisions relating to specific bioethical issues such as medical research with human beings and removal and transplantation of organs, while chapters VIII to XIV include the procedural norms. The Biomedicine Convention is completed by (as of today 4) additional protocols: on the prohibition of cloning human beings (1998), on transplantation of organs and tissues of human origin (2002), on biomedical research (2005) and on genetic testing for health purposes (2008).

Article 6 of the Convention deals with persons who are not able to give consent to a medical intervention. Article 6 §3 stipulates:

'Where, according to law, an adult does not have the capacity to consent to an intervention because of a mental disability, a disease or for similar reasons, the intervention may only be carried out with the authorisation of his or her representative or an authority or a person or body provided for by law.'

The explanatory report to the Convention gives some clarification that is relevant for competence assessment: 'The incapacity to consent referred to in this article must be understood in the context of a given intervention. However, account has been taken of the diversity of legal systems in Europe: in some countries the patient's (factual)¹⁰ capacity to consent must be verified for each intervention taken individually, while in others the system is based on the institution of legal incapacitation, whereby a person may be declared incapable of consenting to one or several types of act. Since the purpose of the Convention is not to introduce a single system for the whole of Europe but to protect persons who are not able to give their consent, the reference in the text to domestic law seems necessary: it is for domestic law in each country to determine, in its own way, whether or not persons are capable of consenting to an intervention and taking account of the need to deprive persons of their capacity for autonomy only where it is necessary in their best interests.'¹¹

In order to protect the fundamental rights of the human being, and in particular to avoid the application of discriminatory criteria, § 3 lists the reasons why an adult may be considered incapable of consenting under domestic law, namely a mental disability, a disease or similar reasons. The term "similar reasons" refers to such situations as accidents or states of coma, for example, where the patient is unable to formulate his or her wishes or to communicate them. If adults have been declared incapable but at a certain time do not suffer from a reduced mental capacity (for example because their illness improves favourably), they must, themselves consent.¹²

¹⁰ Added by the authors

¹¹ Explanatory Report, § 42.

¹² Explanatory Report, § 43.

2.4 Recommendation (99) 4 of the Committee of Ministers of the Council of Europe on principles concerning the legal protection of incapable adults

In the explanatory memorandum to Recommendation (2009)11 on principles concerning continuing powers of attorney and advance directives for incapacity it is considered that the Recommendation (99) 4 continues to be of great relevance, and that it remains entirely up-to-date. Its strength is that it is addressed to all member states and provides detailed guidance on how to reform national legislation. Indeed, it has guided several member states in the preparation of recent legislative reforms. As already stated reference to this recommendation has been made in judgments of the European Court of Human Rights among which Shtukaturov. In this case, the Court concluded : 'Although these principles [of the Recommendation (99) 4] have no force of law for this Court, they may define a common European standard in this area'.¹³ The Working Party preparing Recommendation (2009) 11 proposed therefore to build on that recommendation and to elaborate new principles focusing upon self-determination, in particular upon continuing powers of attorney and advance directives.

The relevant parts of Recommendation (99) 4 read as follows:

Principle 3 – Maximum preservation of capacity

'1. The legislative framework should, so far as possible, recognise that different degrees of incapacity may exist and that incapacity may vary from time to time. Accordingly, a measure of protection should not result automatically in a complete removal of legal capacity. However, a restriction of legal capacity should be possible where it is shown to be necessary for the protection of the person concerned.

2. In particular, a measure of protection should not automatically deprive the person concerned of the right to vote, or to make a will, or to consent or refuse consent to any intervention in the health field, or to make other decisions of a personal character at any time when his or her capacity permits him or her to do so.'

Principle 6 – Proportionality

'1. Where a measure of protection is necessary it should be proportional to the degree of capacity of the person concerned and tailored to the individual circumstances and needs of the person concerned.

2. The measure of protection should interfere with the legal capacity, rights and freedoms of the person concerned to the minimum extent which is consistent with achieving the purpose of the intervention.'

Principle 9 – Respect for wishes and feeling of the person concerned

'3. [This principle] also implies that a person representing or assisting an incapable adult should give him or her adequate information, whenever this is possible and appropriate, in particular concerning any major decision affecting him or her, so that he or she may express a view.'

Principle 13 – Right to be heard in person

'The person concerned should have the right to be heard in person in any proceedings which could affect his or her legal capacity.'

Principle 14 – Duration, review and appeal

'1. Measures of protection should, whenever possible and appropriate, be of limited duration. Consideration should be given to the institution of periodical reviews ...

3. There should be adequate rights of appeal.'

¹³ Explanatory memorandum to Rec (2009)11, §5.

3. Assessing competence¹⁴

3.1 General principles

In this paragraph some elements that can help to determine whether a person with cognitive disorders is still competent, will be explored starting from the assumption that competence assessment has a double goal:

1. *to protect the persons concerned;*
2. *to respect as far as possible their autonomy and capacity.* This means that as far as possible the still existing capacity of a person should be taken into account and that these persons should be treated as any other competent person.

The competence assessment can be founded on four principles:

1. *The assumption that every adult is capable of making his own decisions.*

An adult person is, unless according to the law he is considered not to have this capacity, capable of making his own decisions and handling his own affairs.

2. *The competence to take a certain decision is related to the specific decision and the context of this decision*

The competence assessment is consequently strictly related to the decision that has to be made.

3. *Everyone has the right to be equally treated*

Whether a person is competent or not cannot simply be deduced from his age, physical and/or mental condition or behavior.

4. *Support a person to make his own decisions*


If a person has problems of deciding independently, everything possible should be put into action to help this person to make his own decisions.

3.2 Different dimensions of competence

The question whether someone is competent or not should always be posed in a given situation and be related to a specific activity. Is a person capable of driving a car, buying a house, or living alone? The current knowledge of the cognitive science about mental processes and the function of the brains make it clear that different activities put different mental processes into consideration. Consequently, it is not possible to approach the competence assessment of a person just from one perspective.

1. Competence assessment is not a one way track. It needs to be differentiated according to the possible different tasks and cognitive domains. A person can be incompetent for one task and still be competent for another one.
2. The competence assessment in one specific domain is also related to the difficulty of the tasks in that domain. How complicated are the tasks and how familiar is the person concerned with these tasks? The more complex the task is, the more competence a person needs in order to accomplish it. The degree of difficulty of a task is consequently a very important factor. Also the experience the person has with regard to a specific task influences the competence of a person. Tasks that do not form part of the person's daily activities ask for a higher degree of competence of this person, than every day-tasks. For example, a person is perhaps not competent anymore of making far trips with his car, but may still be competent to drive to the local supermarket.
3. Past experiences have an influence on the capacity

¹⁴ Based on X. Seron, Juristen en oudere personen met cognitieve moeilijkheden, Naar een betere interactie, 2011, Brussel, Koning Boudewijnstichting, 22-27. Praticiens du droit et personnes âgées en difficulté cognitive. Pour des interactions réussies, 2011, 22-27



The more a person is an expert in a specific domain, the longer he will be competent of making decisions in this domain. Consequently, also the history of a person needs to be taken into account when assessing his competence. For example a taxi-driver may be competent to drive for a longer period, than a person whose profession does not require him to driving entire days.

4. The competence of a person is not a given fact, but evolves in time.

The competence of a person with cognitive disorders diminishes over time when the disease evolves into a more serious stage.

5. Competence is context-related

Since competence is context-related, also social, cultural and contextual factors have an influence. For example, a person can be competent enough to make his own meal in his own, familiar, kitchen, but can be totally lost when he has to make the same meal in an unfamiliar environment

How to assess one's competence is consequently a very complex task and cannot be reduced to an all-or-nothing opinion. This is certainly the case for persons with cognitive disorders.

3.3 Medical, psychological and social factors

In assessing the competence of a person for a certain task, at least the following factors need to be taken into account:

1) Medical condition

For each activity for which competence assessment is necessary, the relation between the physical and mental condition of a person and the activity to be performed needs to be addressed. Especially for persons with cognitive disorders, it is recommended to collect information about the cause of the problems, beginning with the question whether the medical condition is caused by a permanent factor or whether there are chances of change - improvement or decline.

2) Cognitive functions and the control over his emotions

Cognitive disfunctions of a person may make him incompetent to decide independently, for example because of problems to speak, to remember, to pay attention. Certain inconsistencies related to age can also cause problems for older persons to keep control over their emotions.

3) Daily-life activities

Daily-life activities play a key-role in assessing one's competence. That is why it is necessary to set up a list of the activities a person still can, and those that he cannot do anymore. It is vital that this description is as detailed as possible.

4) Preferences and wishes

When assessing competence, it is necessary to assess whether the person concerned is still capable of expressing his wishes, values and preferences in a consistent way. It is important that in assessing a person, one should not evaluate the decisions of the person concerned, because these decisions are subjective and are related to the wishes and values of a concrete person. The competence assessment of a person does consequently not regard the content of the decisions, but the coherence of the decision making process.

5) Risk of accidents and need to supervision

If a person with cognitive disorders is not capable anymore of living on his own without any risk for his physical, mental or financial integrity, protective measures need to be considered. In assessing the risks, the social support of the daily environment should be taken into account. Also the question whether the person concerned is aware of the possible risks needs to be taken into account.

6) *Measures to maximize the competences of a person*

If a person has a cognitive disorder or a physical problem, this does not necessarily lead to the conclusion that he needs to be protected. Suitable measures need to be taken, which means that every situation needs to be addressed separately. Drastic measures must be avoided if possible. An important factor to take into account is whether the support of the social environment on a permanent basis is possible. To this effect, experts in the field of supporting persons, such as caregivers and nurses, need to be addressed.

3.4 Competence for autonomy and competence for decision-making by persons with dementia¹⁵

Deciding on the competence of a person is a matter of striking the right balance. This fair balance between the patient's autonomy on the one hand and the protection of this person against making any irrational choices because of his incompetence on the other hand, is needed. Since deciding on the incompetence of a person is not something that happens overnight, it needs a well thought-through consideration keeping in mind all the different aspects of becoming incompetent. Competence does not equate with perfect rationality. Every person has the right to make an unwise or eccentric decision. Therefore the different methods that exist to assess one's competence are only instruments, tools to help better assess the capacity of the person concerned. The assessment itself remains a clinical judgment. Therefore competence assessment should always be carried out by persons with special skills in this complex matter.

Fabrice Gzil argues that persons with dementia have, as any other person, a right to autonomy. Dementia however may reduce the competence to act and decide autonomously. The question 'does this person with dementia has the capacity of autonomy' or 'is this person competent' rises in many contexts. For example to live independently, driving, financial affairs, making up a will, ...The determination of competence is of critical importance, both from the perspective of protection of vulnerable persons, as well as safeguarding the autonomy of these persons as far as possible. In order to better understand the capacity questions for persons with dementia, Gzil poses the question what the relationship is between capacity for autonomy and capacity for decision-making and how dementia may affect both capacities. The main question is whether both types of capacity are one and the same or not. In other words when a person with dementia has lost the capacity to make decisions, is it still possible to respect his autonomy and thus his wishes? May he retain a capacity for autonomy when he cannot decide for himself anymore?

Two distinct categories of authors have addressed this issue: clinicians and philosophers. Being a clinician Paul Appelbaum raised the question whether persons with dementia still can give their consent for medical treatment. Philosophers on the other hand tried to find an answer to the question how capacity can be affected by dementia? The confrontation of the ideas of both categories could be a useful framework for better respecting the autonomy of people with dementia.

1) The clinical approach

According to clinicians one has to consider the doctrine of informed consent. Persons with adequate capacity to decide have the right to make informed choices about their medical care. In contrast incompetent persons should be protected against the harm their decisions could cause to themselves. However, assessing whether a person can give his informed consent can be a challenging task. In order to help clinicians to make this assessment Appelbaum and his colleagues have made a

¹⁵ F.Gzil, Fondation Médéric Alzheimer *Dementia, competence assessment and capacity for autonomy*, Alcove meeting on advance directives and competence assessment, Brussels, 26-27 April 2012.

model of consent-capacity based on the US-case law.¹⁶ According to this model competence assessment is related to four abilities: 1. Understanding: the ability to comprehend the diagnosis and treatment related information 2. Appreciation: the ability to relate this information to one's own situation 3. Reasoning: the ability to evaluate and compare alternatives 4. Expressing a choice: the ability to convey a relatively consistent choice

To implement this model, Appelbaum and his colleagues have developed standardized questionnaires to empirically measure skills in these four domains. The method consists of asking the person with dementia a series of questions that assess these abilities. For instance, in order to assess the competence to understand the risks related to a certain medical treatment, the clinician asks the person with dementia to paraphrase the meaning of the information disclosed: 'Tell me in your own words what I just said about the risks of this treatment.' To measure the ability of reasoning he assesses the ability to compare two options: treatment versus non-treatment and the ability to evaluate how his choices will affect his daily life.

2) *The philosophical approach*

Some philosophers have a very different approach for determining whether a person with dementia still has the capacity for autonomy. For instance, Dworkin¹⁷ recognises that competence is sometimes used in a task-specific sense as the ability to make one part of the decision. But for him competence is a very different matter. It means a more diffuse and general ability, the ability to act out of a general character. For Dworkin competence for autonomy can be defined as the ability to shape one's life according to one's distinctive personality. To organize one's life around a systems of desires and wishes. If you want to know whether a person is still competent, you should ask yourself the question 'does he still have a character? Does he still have critical interest?' Not only things he likes because he finds them pleasurable, but also things he believes his life would have been wasted if they were not present determine whether a person is competent or not. Critical interest therefore can be defined as having a sense of one's whole life. If the choices of a person systematically contradict one-another reflecting no coherence sense of self, then he has presumably lost the capacity of autonomy. An important contribution to this theory of Dworkin was formulated by Agnieszka Jaworska.¹⁸ She agrees with the general line of Dworkin, but she believes that his criterion is too restrictive. For her a person does not need to have a sense of his life as a whole, in order to have a capacity for autonomy. Opinions about critical interests are just opinions about what is good for you. That is about my values and valuing may be quite independent from the entire life of a person. If you want to assess whether a person has the capacity for autonomy, you should only assess whether this person is still a valuer, if this person still cares for something. Since to live autonomously is to live according to one's own values, this is a sufficient condition for capacity for autonomy. For Jaworska a person can still have capacity for autonomy, although he can no longer participate in a concrete activity or take a certain decision. There is no good reason to restrict the right to autonomy only to persons who have the ability to reason, because a third person can help the person with dementia to take decisions or make these decisions for the person according to his values. Capacity for autonomy is best understood not as a full capacity to take decisions from the beginning to the end, but as the capacity to value.


3) *Combining both approaches*

At first sight it seems impossible to combine both approaches. Appelbaum assesses capacity for individual decision-making and not capacity for autonomy. The criteria he puts forward do not help to answer general questions regarding the capacity for autonomy of the person. It only answers the question 'can that person take these decisions alone, or does someone else have to help or decide

¹⁶ P.Appelbaum a.o. *Assessing Competence to Consent to Treatment*, Oxford University Press, 1998.

¹⁷ R.Dworkin, *Life's Dominion: An argument about abortion, euthanasia and individual freedom*, Alfred Knopf, 1993.

¹⁸ A. Jaworska, 'Respecting the Margins of Agency: Alzheimer's patients and the capacity to value', *Philosophy and Public Affairs*, 28 (2), 1999.



for the person with dementia? For Dworkin, it is true that a person with dementia can have no sense about his critical interests, but before that the critical interests gave meaning to the person's life. So the 'early formulated' critical interest of his whole life remains important, even in a stage in which the person with dementia has lost this critical interest. When the person has lost the capacity for autonomy, the critical interests which gave meaning and coherence to the person's life are still important. Therefore, they still need to be respected. Gil proposes the following synthesis. When one is unsure whether a person can make healthcare decisions independently, one should use at least the criteria put forward by Appelbaum. One should ask whether the person with dementia is able to understand, appreciate, reason and express a choice. When this person does not seem able to decide alone, the person designated to make decisions for him should remember the theory of Jaworska that a person still can have capacity for autonomy even if he has lost the capacity to make decisions himself. Before considering the person's past wishes, the representative should consider whether the person still has current values and try to make the decisions according to these values. It is only when the person has no more authentic values, or critical interest that Dworkin's theory can be used. Then the representative should consider the person's past values and/or critical interest.

4. Legal and ethical aspects of competence assessment of persons living with dementia in specific situations

4.1 Competence assessment and healthcare interventions on persons living with dementia

Giving or refusing health care interventions is based on the right to self-determination. This right is widely recognized for instance in article 5 of the Biomedicine Conventions, which stipulates:

'An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it.

This person shall beforehand be given appropriate information as to the purpose and nature of the intervention as well as on its consequences and risks.

The person concerned may freely withdraw consent at any time.'

Based on this right every patient is entitled to make his or her own choices regarding his health care. A physician cannot act without the informed consent of the patient. Also for this kind of decisions one should presume that a patient is competent. Nevertheless situations may occur in which problems arise regarding the competence of a person. For example a person who is diagnosed with Alzheimer's disease, will slowly lose the capacity to make decisions. Does this also lead to the conclusion that this person loses the capacity to make health care decisions or does he still remain competent enough to take these decisions autonomous? Very important hereby is the question who decides whether a person is becoming or is incompetent to make health care decisions and on what such decision is based. Questions also arise about the consequences of a person being considered to be incompetent and how to protect the patient in such case.

The assessment of the competency to make health care choices is a task for the treating physician. More concretely this physician has to evaluate whether the patient understands the information he has given to this patient. If the patient did not understand this information, the physician first has to try to inform the patient in another way, for example by simplifying the way of informing. If the physician thinks that the patient still does not understand the information, then he may conclude that the patient is incompetent of making the particular health care decision. In doing so the physician decides on a case-by-case approach whether or not the patient is capable enough.

4.2 Competence assessment and advance directives drafted by persons living with dementia

1) *Competence assessment at the moment of drafting an advance directive by a person living with dementia*


Perhaps the most significant distinction between the regulation of contemporaneous decisions and those made in advance is that the person seeking justification for an intervention is able to interact with the person during the period of decision-making.¹⁹ This has implications for all of the prerequisites of a valid refusal. First, for contemporaneous decisions, any doubts raised by the decision about the decision-maker's capacity may be dealt with by performing a formal competence assessment. However, when the decision is contained in an advance directive, this option is closed by the very reason that the advance directive becomes relevant. The consequence of this is that, in making a competency judgment the assessor is likely to base his decision on the apparent rationality of the directive. In other words, the competence of the person who drafted the directive will be determined by the *reasonable outcome of choice test*. This test is less respectful of the individuals' autonomy than the *functional test*. The only way to avoid the problem of retrospective assessment based on the outcome of the person's choice is to require a formal assessment of competence for an advance directive to be valid. Most of the EU countries do not require such a formal assessment because this would create a serious barrier for those who want to draft an advance directive. One exception is Hungary where an advance directive is only valid if a qualified psychiatrist has confirmed in a written opinion that the person made the decision in full awareness of its consequences. This medical opinion of the psychiatrist cannot be older than one month (see IV. Advance Directives). Similarly there are no formal requirements that the author of an advance directive be sufficiently well informed to make a reasonable decision.

A controversial question is whether patients with a diagnosis of dementia can at that stage still make up an advance directive. None of the EU member states that have regulated advance directives have specific rules in this regard (see IV Advance Directives). It has to be emphasized again that incapacity is not to be deduced automatically from a diagnosis of dementia or another mental disorder. The fact that, statistically, capacity is frequently impaired in patients with dementia provides reasonable grounds for doubt and prudence. From an ethical and legal viewpoint, however, there is a duty to always assess capacity in each individual case. Reversibility of incapacity can sometimes be observed in progressive disorders such as dementia. Given the possibility of fluctuating capacity in dementia, the capacity should be carefully assessed at the time an advance directive is prepared; assessments should be performed during lucid intervals so as to promote the patient's autonomous decision-making ability. Written records should be kept of who carried out the assessment of capacity, and of the criteria and methods used; if any doubts remain, another expert should be consulted.²⁰

Some people deny as a matter of principle that it is possible to imagine the life of a person with dementia, and they therefore regard an advance directive merely as one indication, among others, of "presumed wishes". They deny that the advance directive can be strictly binding. In response to these doubts, it may be objected that there is always a discrepancy between reality as it is imagined and experienced, and that decisions are never made with full knowledge of the facts. In addition, advance directives are generally prepared by elderly people. It can be assumed that they have already experienced illness – perhaps also dementia – among their relatives or friends, and that they may also have been seriously ill themselves. These experiences will have shaped their ideas of a good life and a good death, and the advance directive will be an authentic expression of these values. It should also be borne in mind that a person confronted with early-stage dementia retains mental

¹⁹ A.R.Maclean, 'Advance directives and the rocky waters of anticipatory decision-making', *Medical Law Review*, 2008, 13.

²⁰ Swiss National Advisory Commission on Biomedical Ethics, 'Advance Directives. Ethical considerations concerning the new adult protection law, with particular reference to dementia', Opinion n° 17/2011, Bern, May 2011, Idem, 18-19



capacity and thus still has the opportunity to draw up an advance directive, in the knowledge that dementia leads to a loss of capacity and aware of the likely course of the disease. Initial experience and knowledge of illness are thus present. For these reasons, but also in the interests of preventing a loss of autonomy, it should be emphasized that wishes for the future, as formulated by the person concerned according to his or her values, personal experience and preferences, are of greater weight than an assessment by third parties of what the person concerned would have decided in this situation if he or she had had mental capacity. For an assessment of this kind remains tied to an external perspective.²¹


2) *The personal identity problem and competence assessment at the moment of implementing (or not) an advance directive drafted by a person living with dementia*²²

The ‘personal identity problem’ has been much discussed. The argument is that some incompetent persons will, by virtue of their illness or disability, experience a loss of personal identity so that they cannot be said to be the same person as the author of the advance directive purporting to govern their care. To implement the advance directive therefore would not be an exercise of self-determination, but rather the illegitimate imposition of one person’s autonomous choice on another person. The personal identity problem is particularly applicable to patients suffering from dementia. Two responses to the personal identity problem have been advanced: one absolute, and one a compromise. Ronald Dworkin rejects the idea of a loss of personal identity and instead argues that a person’s ‘critical interests’ survive the loss of capacity and that respect for these important interests requires the implementation of an advance directive that promotes them. Søren Holm has responded that ‘it seems equally plausible ... that the critical interests just disappear’ or only remain if the underlying reason for that critical interest remains. Alternatively, Allen Buchanan’s compromise position accepts that personal identity can be lost. If the resulting individual is not a ‘person’ – for example is in a persistent vegetative state – then an advance directive protecting the original person’s ‘surviving interests’ which survive the loss of personal identity can be implemented without raising the specter of imposing one person’s choices on another *person*. However, where the resulting individual does meet the criteria for personhood, the personal identity problem does raise concerns and the moral force of the advance directive will be lessened as the force of its autonomy-based rationale is weakened. A relatively small subset of those creating advance directives will fall into this problematic category of those who have lost personal identity but continue to possess the attributes of personhood.

Obviously, if the autonomy-based rationale for advance directives is weakened even only in a small portion of cases, this is of grave concern. A more widespread problem though, is the potential for conflict between the autonomy-rationale supporting implementation of an advance directive, and the present welfare interests of its now incompetent author (whether or not the incompetent individual retains the attributes of personhood). In the case of advance refusals of treatment, in most cases the instructions contained in the advance directive will coincide with the incompetent individual’s best interests, as will have been the competent author’s intent. The coincidence of autonomy and welfare will not always be present, however. How should conflicts between autonomy and welfare be resolved in this context? According to Dworkin, again the individual’s critical interests, which are protected by the autonomous choice contained in the advance directive, are more important and should take precedence over any experiential welfare interests. Rebecca Dresser has argued in response that autonomy should not have primacy over obligations owed to protect the welfare of incompetents and to treat them with compassion. The author of an advance directive refusing treatment may be unaware of the threat to her future welfare if the directive is

²¹ Swiss National Advisory Commission on Biomedical Ethics, ‘Advance Directives. Ethical considerations concerning the new adult protection law, with particular reference to dementia’, Opinion n° 17/2011, Bern, May 2011,19

²² P. Lewis, ‘Medical Treatment of Dementia Patients at the End of Life: Can the Law Accommodate the Personal Identity and Welfare Problems?’, *European Journal of Health Law* 2006, vol. 13, 219-234.



implemented. Even if the author assessed his welfare interests in advance, the problem remains as the individual's previous assessment of her future welfare may be flawed: 'people may be mistaken about their future experiential interests as incompetent individuals.'

Also LEMMENS refers to the possible conflicts and problems that arise with regard to advance directives, competence assessment in the context of persons with dementia. After having explored the problems and conflicts, he discusses the position of the German National Ethics Council.²³ The German National Ethics Council defends a compromise position, according to LEMMENS. According to the Council, an advance refusal cannot be implemented if the incompetent patient is showing a will to live. However, the directive remains to be implemented if some conditions are met. These requirements entail that the conditions of implementation have to be formulated clearly, that the directive has to expressly provide that the directive is to be implemented even if later on the declarant is showing a will to live, that the directive is in the written form or in a form that is just as reliable (e.g. a video fragment) and, finally, that the directive has been preceded by a suitable advice (e.g. from a physician). In other words, the directive can only be implemented, if the author fully understood its range and possible consequences.

After considering the current and steadfast wishes of an incompetent patient which are incompatible with an advance directive could be a valid reason to (temporarily) override the directive. This is the case if, for instance, the advance directive is not clearly formulated, does not envision possible later behaviour of the declarant, is not in the written form and if at the same time the now incompetent patient expresses himself in a consistent and repeated manner which is clearly contradictory with his previous directive. On the other hand, a written advance directive wherein the declarant has clearly stated his will and wherein he has envisioned his current behaviour, will have to be followed, even if the incompetent patient is behaving himself in a repeated and consistent manner. Before making a decision the physician should opt for a multidisciplinary approach and make notes in the patient's medical record for transparency reasons. Moreover, the infringement of the patient's precedent autonomy should be reduced to a minimum. The advance directive should regain effect if the incompetent patient's divergent behaviour disappears and if the conditions for implementing the advance directive arise again. After all, the advance directive was not revoked by the patient because of his incompetency to do so (see below). Only its implementation has been postponed.

3) *Competence assessment and the revocation of an advance directive by a person living with dementia*

Another issue is whether the advance directive is revocable once the person becomes incapacitated.²⁴ It is a legal requirement in all EU member states that, to be legally binding, the author must have the requisite capacity to make the decision. Since intentional revocation requires a decision, the person at that point must be legally competent. This means that the onset of incapacity *should* make the advance directive irrevocable even if the person subsequently changes his mind which may require an advance directive to be implemented without the patient's co-operation. One could argue that the capacity needed to make an advance refusal is greater than the capacity required to alter or revoke that refusal afterwards: since a refusal is likely to have more grave consequences than an acceptance of treatment, capacity must be greater for a valid refusal than for the revocation. In accordance with this, many EU member states that have regulated advance directives allow the revocation in an informal way, even when the author has become incapacitated. Never a formal assessment of the capacity to revoke is required.

²³ C. Lemmens, 'End-of-Life Decisions and Demented Patients. What to Do if the Patient's Current and Past Wishes Are in Conflict with Each Other?' *European Journal of Health Law*, 2012, Volume 19, Issue 2, 177–186.

²⁴ A.R.Maclean, 'Advance directives and the rocky waters of anticipatory decision-making', *Medical Law Review*, 2008, 19.

4.3 Competence assessment and driving by persons living with dementia

1) *General considerations*²⁵

In later life, with respect to the maintenance of mental and physical health, social contacts and quality of life, driving capacity may become a critical factor. However, perhaps as a result of the rapidly increasing number of older drivers in the developed world, many European countries introduced obligatory health checks for the elderly. This might be surprising, as, on the one hand, old-aged drivers play a subordinated role in causing road accidents; rather, in modern traffic, they are at increased risk of being the victim in the traffic, also as pedestrians, bicyclists or train users. Since many of the elderly reduce driving voluntarily, it is also debatable whether the investments in screening justify the earning of a reduced accident rate, if it occurs at all.


Many aspects should be taken into account: neuropsychological functions like attentional functions and visual processing, visual acuity, insight into disease and the presence of somatic disorders and drug treatment.

While many regulations exist with regard to health checks of the elderly in Europe, there is not much empirical research supporting this. And security aspects also apply to pilots licenses for planes and boats. Do countries with regulations for driving checks in the elderly also check for the use and the possession of firearms? While there are no obligatory checks with regard to this, those exist for driving license.

Nevertheless, European Council Directive 91/439/ EEC constitutes the rationale for national criteria regarding medical fitness, which are supposed to be required for driving (White and O'Neill, 2000). This directive is not age-related and primarily focused on somatic diseases. Moreover, with regard to the process of driving skills' assessment in the European elderly, a significant transnational heterogeneity can be assumed. This affects the content of health checks which may consist of a "general", in particular cases poorly operationalized, check-ups or self-reporting questionnaires as well as neurological and psychiatric examinations. Would it make sense to foresee a regular screening for signs of dementia? Is there a consensus regarding age at entry, and following time intervals for health check-ups? And how heterogeneous are the regulations applied with regard to the obligation of reporting any illness to the authorities, when potentially affecting driving skills?

Preserved motor, perceptual, and cognitive functions are necessary for driving competence. Impairment in such areas affects the ability to drive and may cause accidents and fatal crashes. Dementia is a well-recognized risk factor for unsafe driving, although some early-demented individuals retain driving capacity during the initial stages of disease. In general, subjects with dementia are poorer drivers than cognitively normal people, and increasing attention has been given to driving capacity and cognitive impairment. Crash risk is proportional to the severity of dementia. The problem, however, consists in estimating fitness to drive in persons with mild dementia. Physicians are constantly faced by situations in which they are asked to decide on whether the elderly should give up driving. This is a key issue in clinical practice with the elderly, since it affects the freedom to circulate and also some aspects of self-esteem of people who have always been independent. A growing body of literature supports the utility of neuropsychological assessment to predict driving competence of elderly with early-stage cognitive decline. Neuropsychological testing provides a useful instrument for diagnosis and prognosis in geriatric assessment. Because of the increasing number of elderly at risk for driving impairment, the consensus on objective tests for driving assessment is critical. Relevance of neuropsychological measures in the evaluation of fitness to drive has not yet been established, nor is a 'Test Stand Battery' predictive of safe driving capacity available. Also, there is no consensus by investigators and professionals on whether old people with mild dementia should be prohibited to drive.

²⁵ M.Silva, J.Laks & E.Engelhardt, "Neuropsychological tests and driving in dementia: a review of the recent literature", *Rev Assoc Med Bras* 2009; 55(4), 484-488



A diagnosis of dementia is not in itself necessarily a reason to stop driving. What matters, from both a legal and a practical point of view, is whether or not an individual is still able to drive safely. For experienced drivers, driving may seem to be a largely automatic activity. In fact, driving is a complicated task that requires a split-second combination of complex thought processes and manual skills.

To drive, a person needs to be able to:

- *make sense of and respond to everything they see*
- *'read the road'*
- *follow road signs*
- *anticipate and react quickly to the actions of other road users*
- *take appropriate action to avoid accidents*
- *remember where they are going.*

Many people with dementia retain learned skills and are able to drive safely for some time after diagnosis. However, as dementia progresses it has serious effects on memory, perception and the ability to perform even simple tasks. People with dementia will, therefore, eventually lose the ability to drive. The stage at which this happens will be different for each person with dementia.

An assessment is not like a driving test. It is an overall assessment of the impact that the dementia is having on a person's driving performance and safety, and it makes some allowances for the bad habits that drivers get into.

Many people with dementia choose to stop driving because they begin to find it stressful or they lose confidence. A person should consider stopping driving if:

- *they feel less confident or more irritated when they drive*
- *they feel confused if there are road works, for example, on a familiar route*
- *they feel worried about having an accident.*

A person who feels like this will need support and understanding from their carer and family members. They may feel bad about stopping driving if they are accustomed to being independent, or if they have always driven their partner or family around. However, it is better to travel safely on public transport than risk an accident in a car.

Someone with dementia can take steps to minimize their risk through driving. Short drives on familiar roads at quiet times of the day generally present fewer problems than long, unfamiliar journeys or journeys in heavy traffic.


People on certain types of medication, such as night sedation or drugs for anxiety, depression or other psychiatric disorders, may find that their driving ability is affected.

Some people who have been assessed as being unsafe still refuse to stop driving, even if those around them have tried to encourage them to stop, and have pointed out alternatives. This can be a very difficult and upsetting situation. Unfortunately, there are no straightforward solutions. The best action to take will depend on the individual involved.

2) Legal consequences of a diagnosis of dementia regarding the license to drive

Dementia and driving safety is of particular concern to society. The question arises whether the diagnosis of dementia has legal consequences²⁶ regarding the license to drive of the person concerned. We have looked for an answer to this question in different European jurisdictions.

²⁶ We do not deal with the professional license to drive here because obviously stricter rules exist in this regard in most jurisdictions.



When a diagnosis of dementia has been posed the authorities responsible for safe driving such as the police can react in different ways. One of them is the withdrawal of the license, either automatically or after a case-by-case decision. Another possibility is to restrict the validity of the driving license in time and/or in space. Still another possibility is not to react at all and leaving it up to the patient and his relatives and caregivers. A preliminary condition for taking a measure by the competent authorities is that they have in one or another way access to the health information of the person concerned. Also in this respect different possibilities can be distinguished. A first possibility is the notification of the diagnosis of dementia by the treating physician or the patient himself (or a relative). This notification can be either on an obligatory or a voluntary basis. If the treating physician notifies the diagnosis he can do so either with the consent of the patient or without his consent or even his knowledge. Still another distinction is notification to a health inspectorate that in turn can notify the diagnosis to the road safety authorities or directly to the latter. A second possibility to inform the competent authorities of a diagnosis of dementia is by submitting persons who request a driving license or the renewal of an existing one to a health examination either obligatory or voluntary.

4.3.1. Access to the diagnosis of dementia by the competent authorities

✓ After notification

In all European jurisdictions a diagnosis of dementia is protected by the obligation of the treating physician to respect medical secrecy and confidentiality. The mutual relation of trust between the physician and a patient is based upon this obligation. Article 8 of the European Convention of Human Rights obliges the member states to take positive measures to legally protect medical secrecy. A legal requirement for physicians to notify each diagnosis of dementia to a health inspectorate or a road safety inspectorate is too disproportional to be in accordance with article 8 of the Convention. If such an obligation would be limited to a diagnosis of dementia and would not exist for other diseases that can create risks for driving safety also article 14 (prohibition of discrimination) would be violated.


To our knowledge no such blunt obligation to notify a diagnosis of dementia to the competent authorities exists in European jurisdictions. However in some countries broader formulated obligations exist. For instance, in Finland since 2004, doctors have been legally obliged to report to the police any patient with a medical condition which makes him or her unfit to drive. Whilst many doctors object to this obligation, hundreds of reports have been made, resulting in numerous withdrawals of license, some of which were for people with dementia.²⁷ Also in the Czech Republic, general practitioners are obliged to report to the driving authorities any patient whose capacity to drive could be affected by their medical condition.²⁸ Although such a measure may be compatible with non-discrimination requirements it is questionable whether it is with the protection of privacy. A more moderate and therefore less questionable obligation exists in Denmark. If the treating physician considers the person incapable of driving safely the doctor is obliged to inform the Public Health Medical Officers. They will consider the case, before forwarding it to the police.²⁹

Another approach in Europe which is more acceptable from the point of view of protection of medical secrecy and confidentiality consists of granting the possibility to physicians to notify a diagnosis of dementia or whatever medical condition that may create a risk for safe driving to the competent authorities. This possibility to notify exists when respecting medical secrecy concerning a diagnosis of dementia may create a danger for the person himself or third persons because the patient continues to drive although in that particular case there is evidence that he is not capable to do so in a safe way. Most of the times this possibility to notify is not based on statutory law but is 'judge made law'. German law offers a good example of this approach. In a court case involving a

²⁷ www.alzheimer-europe.org -policies in practice -country comparisons – restrictions of freedom-driving Finland

²⁸ www.alzheimer-europe.org -policies in practice -country comparisons – restrictions of freedom- driving- Czech Republic

²⁹ www.alzheimer-europe.org -policies in practice -country comparisons – restrictions of freedom- driving- Denmark



woman with schizophrenia, the Federal High Court ruled that a doctor could inform the traffic authorities of a person's unfitness to drive. This could equally apply in cases of dementia. The judgment was as follows: 'A doctor, despite his basic duty to maintain confidentiality, can be justified, according to the principles on the weighing up of conflicting duties or interests, in informing the traffic authorities if his patient drives a motor vehicle on the road despite no longer being capable, on account of his illness, of driving a motor vehicle without endangering himself and others. The precondition, however, is that the doctor has previously made the patient aware of the condition of his health and of the dangers that would arise if he drove a motor vehicle, unless, from the outset, there would be no point – due to the nature of the illness or lack of understanding on the part of the patient - in the doctor trying to persuade him.'³⁰ This judgment was justified on the grounds that although confidentiality forms the basis for the relationship between doctor and patient, the doctor can be bound by a higher interest which is to protect public safety. The interest in preventing a person who is unfit to drive from driving is considered to outweigh the interest the public and the individual have in the doctor's maintenance of confidentiality in this case.³¹ Based on the same '*conflict of duties or interests*' reasoning, physicians are in position to notify a diagnosis of dementia in countries such as Belgium and Cyprus. The advantage of such an approach is its flexibility. A danger is that it lacks objective criteria and may lead to arbitrary decisions by physicians when notifying (or not) a diagnosis of dementia.

In other countries like in France the treating physician is legally bound to inform and warn the person of the risk that a cognitive impairment may affect his/her ability to drive. At every medical consultation or when modifying treatment, the doctor must renew the information. The doctor may be liable under civil or criminal law if it is proved that he failed to inform the person of the risks normally foreseeable. Nevertheless, it is still the person's responsibility to inform the relevant authorities because the obligation to respect medical secrecy prevents the physician to inform the competent authorities.³² This solution lays the responsibility to inform the competent authorities entirely upon the patient or his relatives and may create a false feeling of reassurance because the treating physician has no means to control whether notification by the patient has been made or not. In England the following intermediate solution exists. Once a person who holds a current driving license is diagnosed as suffering from dementia, he is legally obliged to inform the Driver and Vehicle Licensing Authority (DVLA). The same applies if he wishes to obtain a new license. If a person who has been diagnosed as having dementia fails to report the diagnosis and also carries on driving against the advice of his doctor, that doctor may inform the DVLA if there is a significant deterioration in the person's condition. Other people, such as a family member, a neighbor or a police officer, who are concerned about a person's ability to drive, may also contact the DVLA.³³

✓ *After a medical examination*

Access to health information may also be guaranteed by making the initial request for a license to drive or its renewal dependent upon a health examination. An important legal problem here is how to prevent discriminatory measures based on medical condition and/or age. The most straightforward solution is to make any request for a driving license (initial request and request for renewal) dependent upon a health examination. Such a general rule exists in Denmark where before a person can be issued with a driving license, he must pass a medical examination.³⁴ In this way no one is discriminated. A disadvantage may be that this is probably a very costly procedure. Another solution is to limit the validity of a driving license until a certain age and make its renewal dependent upon a medical examination. In Denmark a driving license is normally valid until the person reaches the age of 70. When the person reaches 70 years of age, the driving license can be extended by four


³⁰ BGH, Urt.v. 8.10.1968 – VIZR 168/68 – Schizophrenie (KG Berlin).

³¹ www.alzheimer-europe.org -policies in practice -country comparisons – restrictions of freedom- driving- Germany

³² www.alzheimer-europe.org -policies in practice -country comparisons – restrictions of freedom- driving- France

³³ www.alzheimer-europe.org -policies in practice -country comparisons – restrictions of freedom- driving- UK-England

³⁴ www.alzheimer-europe.org -policies in practice -country comparisons – restrictions of freedom- driving- Denmark



years if the person is 70 years' old; by two years if the person is 74-80 years' old and by one year, if the person is more than 80 years' old. A comparable approach exists in Spain where between the age of majority (18) and 45 years, a medical examination is required every 10 years; between the age of 45 and 70, every 5 years and for those older than 70 every 2 years.³⁵ This is a much more nuanced approach than a general measure that exists in the Czech Republic where drivers over the age of 60 have to undergo regular medical check-ups and this can be controlled by the police.³⁶ There are also countries where no general obligation to be submitted to a medical examination exists such as Austria, France and Germany. However before in Austria a license can be withdrawn or restricted on the grounds of insufficient suitability for health reasons, a report issued by a doctor must be obtained.³⁷ Under the provisions of the French Highway Code, the préfet, on the basis of convincing relevant information that someone may be unable to drive, may decide to order a medical examination by the departmental primary medical commission to assess the person's mental state. The préfet can also order an assessment if the person is involved in a traffic accident. When there is a danger for the person's health and security, the doctor or a relative may also send a request for medical examination to this commission. Based on that medical assessment, the préfet may pronounce the renewal of the license with regular medical control, the suspension or the revocation of the driving license.³⁸

4.3.2. Consequences of a diagnosis of dementia upon the license to drive

- ✓ *Automatic withdrawal of the license to drive or a measure with a comparable result*

To our knowledge the diagnosis of dementia does not automatically lead to the withdrawal of the driving license of the person concerned in European countries. The right to self-determination and privacy (article 8 European Convention on Human Rights) would oppose such an automatic measure. There are nonetheless countries where measures exist that may have this result. In the Netherlands a diagnosis of dementia makes a person ineligible to drive a motorized vehicle. In case of doubt or suspicion that a person is in the early stage of dementia, a specialist assessment is advised which includes a driving assessment.³⁹ In Bulgaria drivers must have the necessary knowledge, skills and behavior to enable them *inter alia* to comply with all the factors that affect the driver's behavior, so as to ensure at any given time maximum security conditions when driving and not to endanger the safety of road users and to be careful and cautious with regard to vulnerable people such as pedestrians and drivers of two-wheeled vehicles. People with dementia who do not meet the above conditions are not permitted to drive according to Bulgarian legislation.⁴⁰ According to §4 of the German Tenth Road Traffic Law of 19 December 1952 (and subsequent amendments), the traffic administration authorities must withdraw the license of any person who reveals himself to be unfit to drive. The license expires immediately on withdrawal. The authorities have the right to check a person's ability to drive.⁴¹

- ✓ *Obligatory medical recommendation to stop driving*

³⁵ S. DEFLOOR, et al., 'Patient Rights in the EU- Spain', *European Ethical-Legal Papers* N°15, Leuven, p.13

³⁶ www.alzheimer-europe.org -policies in practice -country comparisons – restrictions of freedom- driving- Czech Republic

³⁷ www.alzheimer-europe.org -policies in practice -country comparisons – restrictions of freedom- driving- Austria

³⁸ www.alzheimer-europe.org -policies in practice -country comparisons – restrictions of freedom- driving- France

³⁹ www.alzheimer-europe.org -policies in practice -country comparisons – restrictions of freedom- driving- Netherlands

⁴⁰ www.alzheimer-europe.org -policies in practice -country comparisons – restrictions of freedom- driving- Bulgaria.

⁴¹ www.alzheimer-europe.org -policies in practice -country comparisons – restrictions of freedom- driving- Germany

In Denmark the treating physician must recommend the person with a diagnosis of dementia to stop driving. If the patient does not want to stop driving and the physician, the relatives or the police find him unable to drive they can refer him to a consultative driving test.⁴²

✓ *A medical examination and/or driving test to evaluate ability to drive*

In other countries a diagnosis of dementia may be followed by a medical examination in order to control the ability of the patient to drive. In Finland a person with dementia can keep his driving license if his dementia is mild (this usually means an MMSE score of more than 20), there is information from the relatives and friends that he is driving safely and has no traffic offences due to dementia and he has undergone a clinical examination by a doctor (usually a neurologist or geriatrician). This examination includes a clock drawing test (to reveal possible agnosia). In case of doubt, an 'on the road' driving test or laboratory traffic test is carried out.⁴³ In Italy, to avoid the risk of harm to themselves or others resulting from people with dementia driving a car, a relative (up to fourth degree), the guardian or the prosecutor may file an application to the Office of Motor Vehicles, which in turn will inform the person concerned of the need to undergo a medical test at the Local Medical Committee for Driving Licenses (established in each province at the local health unit) and asking him/her to refrain from driving pending a decision. Article 119 of the Highway Code states that the primary care doctor can request that the person with dementia goes to the Local Medical Committee for Driving Licenses if the outcome of clinical, instrumental and laboratory tests arouses doubts concerning that person's suitability and ability to drive safely. People with mild dementia may be permitted to drive for just one year or even a shorter period of time but must report any deterioration in symptoms and are advised not to drive alone, either at night or in bad conditions.⁴⁴ Instead of a medical examination one can also make use of already available medical information in order to assess the ability to drive. In England the Driver and Vehicle Licensing Authority sends a questionnaire to the person who has notified being diagnosed with dementia and requests permission to obtain medical reports from his/her doctor and specialists. A formal driving assessment may also be required. If on the basis of that medical information, the DVLA decides that the person should be allowed to continue driving, it issues a license, which is valid for a period of one year.⁴⁵

⁴² Goffin and Nys, Denmark, 11

⁴³ www.alzheimer-europe.org -policies in practice -country comparisons – restrictions of freedom- driving- Finland

⁴⁴ www.alzheimer-europe.org -policies in practice -country comparisons – restrictions of freedom- driving- Italy

⁴⁵ www.alzheimer-europe.org -policies in practice -country comparisons – restrictions of freedom- driving- UK England

5. Conclusions & main recommendations⁴⁶

Competence Assessment for Persons living with Dementia: Competence assessment has the goal, on the one hand, to protect the person's rights but on the other hand to, in the best way, respect their autonomy. Therefore, deciding on the competence of a person is a question of **striking the right balance between the autonomy of the person living with dementia and the protection of this person.**

- [1] **A person diagnosed with dementia should not automatically be considered incompetent to exercise her/his right to self-determination.** Presumption of competence needs to be guaranteed for people with dementia during the course of their disease.
- [2] **When the person living with dementia is not able to decide alone, the selected healthcare proxy should be involved.** Only when the person living with dementia has no longer authentic values, or critical interest, the proxy and the treating healthcare professional should rely on the advance directive (if present) or the person's past values and critical interest.
- [3] **Competence needs to be assessed on the basis of a case-by-case approach and should be repeated for every important care or treatment decision.**
- [4] **When assessing the competence of a person, contextual factors need to be taken into account including medical, psychological and social factors.**
- [5] **Whether a person is competent to make a decision regarding care and treatment needs to be assessed by a qualified and skilled healthcare professional.** In many cases, this will be the treating physician. However, this person should not decide alone in all cases and situations. If deemed appropriate, he or she needs to take into account the opinion of others (colleagues, proxies or relatives, nurses, social workers, psychologists, etc.)
- [6] **Additional research on the development and validation of efficient and practical assessment tools are needed, especially for people with a progressive cognitive condition like dementia.**

⁴⁶ These recommendations have been formulated with an international and multidisciplinary group of experts

IV. ADVANCE DIRECTIVES

1. Regulation of advance directives in Europe

Key messages

Advance directives & Dementia

Advance directives

- can be a major improvement in respecting the person with dementia as it gives the opportunity to express wishes on matters considered as being important for the person,
- are ideally part of an ongoing process and dialogue with relatives, doctors, and other caregivers,
- and advance care plans become intertwined tools to support the autonomy of people with dementia,
- need to be reviewed regularly.

1.1 Introduction and terminology


Structural ameliorations in health (care) and living conditions, demographic and social changes have led to a longer duration of human life than ever. As a consequence the number of people living with dementia and Alzheimer's disease will continue to grow. Medical progress has resulted in more possibilities to cure diseases. At the same time there has been a growing attention in the last decades for autonomy and the rights of patients, whereas the Western society has become more and more pluralistic. All these developments taken together have resulted in much more interest for the so called 'incapacity' problem in policy, regulation and medical and legal practice than ever before in European countries and on the global and European level as well. European countries are confronted with comparable questions while at the supranational level treaties and recommendations may help to frame the national legal response.

A number of instruments have been developed to enable competent persons to express their wishes and will in advance. All these instruments that provide guidance or rules for medical decisions to be made after the person becomes incapacitated are called *advance directives*. Some prefer the expression '*advance (health) care directive*' because the notion 'advance directive' might not fully express the health care context within which the expression of wishes arises.⁴⁷ However, in the context of this report it is clear that advance directives are always *advance care or treatment directives*.

Usually two main types of advance directives are distinguished: instructional and proxy directives.⁴⁸ An *instructional directive* provides particular details about wishes and/or preferences for treatment decisions that might be anticipated while a *proxy directive* designates one or more individuals to make medical decisions for the now incompetent patient. Instructional advance directives can include instructions regarding an intervention the patient would request for or consent to. These are so-called *positive advance directives*. The most discussed example of a positive advance directive is an advance request for euthanasia. Because euthanasia is illegal in Europe (with the well known

⁴⁷ See P.HANAFIN, 'End-of-life decision-making in contemporary Ireland' in S.NEGRI, *Self-Determination, Dignity and End-of-Life Care. Regulating Advance Directives in International and Comparative Perspective*, Leiden-Boston, Martinus Nijhoff, 2011, 213.

⁴⁸ R.ANDORNO e.a. 'Advance health care directives: towards a coordinated European policy?' *European Journal Health Law*, 2009, 207-227.



exception of Belgium, Luxembourg and the Netherlands) it is out of the scope of this report, as well as positive advance directives in general. The most frequently mentioned and discussed type of an instruction directive is the *negative advance directive*. In this type of advance directive, a person refuses a given medical intervention that he would be in need of at a moment when he is not competent anymore to decide on his own. The legal framework of this kind of advance directives in Europe and the EU member states is the central issue in this part of the report.

Advance directives are legal instruments to shape so called *advance (health) care planning*, but they are certainly not the only one. Another instrument is a *treatment limit order* such as a DNR (do not resuscitate) code. Although negative advance directives and treatment limit orders are both instruments that give shape to advance care planning, they have to be clearly distinguished. In a negative advance directive a person refuses a given treatment that is medically indicated when he is not competent anymore to decide on his own. In a treatment limit order the medical team indicates which medical interventions are not medically indicated anymore for a given patient who may or not be incompetent. Treatment limit orders are outside the scope of this report.

Advance directives are gaining greater recognition in patient care than in medical research, where their legal status is still somewhat unclear.⁴⁹ Advance directives for research are not dealt with in this report.

- *Before proceeding to a legal analysis of advance directives, it is worth pointing out that there are several different situations in which an advance directive could be of interest.*
 - ✓ *First, a person might have drafted an advance directive for situations where he has temporarily lost consciousness but wishes to refuse certain treatments. An example would be an advance directive refusing blood products for a Jehovah's Witness during a surgical intervention (of course, if the directive is followed in a case where transfusions are essential, the loss of consciousness is very likely to become permanent).*
 - ✓ *Second, a patient might be suffering from a degenerative physical illness such as motor neurone disease 'locking up' the patient in his body, with no physical ability to communicate anymore although still mentally competent. In such a situation he may be able to withdraw treatment by an advance directive.*
 - ✓ *Third, a patient might have a more general directive stating that, should he enter in a permanent vegetative state, he would all treatment to stop. Fourth, a patient may be terminally ill due to for instance a lung cancer and refuse any life prolonging care in an advance directive.*
 - ✓ *Finally, a patient might fear the permanent irreversible loss of competence brought about by dementia.⁵⁰*
- *Although some of these categories are a lot more problematic than others from a practical, legal and ethical point of view, this report deals with the ethical and legal questions raised by advance directives regardless of the specific type of disease but with a focus on some specific issues relating to dementia.*

⁴⁹ See S.Lotjönen, 'Medical research on patients with dementia – the role of advance directives in European legal instruments', *European Journal of Health Law*, 2006, 235-261.

⁵⁰ Based on D.Shaw, 'A direct advance on advance directives', *Bioethics*, 2012 (26), 269.

1.2 Advance directives and the Council of Europe.

1.2.1. European Convention on Human Rights

The ECHR does not contain a provision regarding advance directives but nevertheless the Convention is more than relevant to this issue because of article 8 which provides:

- 1 *Everyone has the right to respect for his private and family life, his home and his correspondence*
- 2 *There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.'*

In the assisted suicide case of *Pretty v. United Kingdom*, the ECtHR found that this right to respect for one's private and family life includes a right to self-determination: 'Though no previous case has established as such any right to self-determination as being contained in article 8 of the Convention, the Court considers that the notion of personal autonomy is an important principle underlying the interpretation of its guarantees'.⁵¹ In a paragraph which may be of particular interest for advance directives and dementia, the Court held: 'it is under article 8 that notions of quality of life take on significance. In an era of growing medical sophistication combined with longer life expectancies, many people are concerned that they should not be forced to linger on in old age or in states of advanced physical or mental decrepitude which conflict with strongly held ideas of self and personal identity'.⁵² The importance of the right to autonomy in the case-law of the Court has increased since then. More specifically, the ECtHR has stated that through the concept of human dignity and human freedom, a right to autonomy can be deduced from the Convention in general. This new and broader approach can be read in the judgment of *Jehovah's Witnesses of Moscow and others vs. Russia* of 10 June 2010.⁵³ The Russian authorities had refused the legal recognition of an entity of Jehovah's Witnesses *inter alia* because they incited their members to refuse lifesaving blood transfusions. The Court decided that the decision to refuse the legal recognition violated the individual's right to autonomy. It stated: 'The very essence of the Convention is respect for human dignity and human freedom and the notions of self-determination and personal autonomy are important principles underlying the interpretation of its guarantees (...) The freedom to accept or refuse specific medical treatment, or to select an alternative form of treatment, is vital to the principles of self-determination and personal autonomy'.⁵⁴ Next to this, the Court also considered advance directives. Since Jehovah's Witnesses always carry what is called a 'No blood' card with them, stipulating that under no conditions do they want a blood transfusion the Court stated: 'designed as an advance medical directive, the card merely certified the choice that the patient had already made for himself or herself, namely to refuse any transfusion of blood or its components. It did not delegate the right to make any other medical decision to anyone else, but designated the patient's legal representative who could ensure, in case of the patient's unconsciousness or inability to communicate, that his or her choice of medical treatment be known to, and respected by, the medical personal'.⁵⁵

⁵¹ *Pretty v. the United Kingdom*, Appl. No. 2346/02, 29 April 2002, Grand Chamber, ECtHR, §61; H.J.J. Leenen, "Assistance to Suicide and the European Court of Human Rights", *European Journal of Health Law* 9(3) (2002) 262.

⁵² *Pretty v. the United Kingdom*, Appl. No. 2346/02, 29 April 2002, Grand Chamber, ECtHR, §65 (emphasis added)

⁵³ J. Dute, "ECHR 2010/17 Case of Jehovah's Witnesses of Moscow v. Russia, 10 June 2010, no.302/02 (First section)", *European Journal of Health Law* 17(5) (2010) 507-513.

⁵⁴ *Jehovah's Witnesses of Moscow v. Russia*, Appl. No 302/02, 10 June 2010, Grand Chamber, ECHR, § 135.

⁵⁵ See on this judgment, T.Goffin, 'Advance directives as an instrument in an ageing Europe', *European Journal of Health Law*, 2012, 134-135.

1.2.2. The European Convention on Human Rights and Biomedicine

1.2.2.1 Introduction

Two articles of this Convention play an important role at the moment that a person is not capable anymore or is in the process of becoming incapable of making healthcare decisions independently, namely article 6 and article 9.

1.2.2.2 Article 6 – Protection of persons not able to consent

Article 6 § 3 stipulates:

‘Where, according to law, an adult does not have the capacity to consent to an intervention because of a mental disability, a disease or for similar reasons, the intervention may only be carried out with the authorisation of his or her representative or an authority or a person or body provided for by law. The individual concerned shall as far as possible take part in the authorisation procedure.’

Article 6 § 5 provides:

‘The authorisation referred to in paragraph 3 above may be withdrawn at any time in the best interests of the person concerned.’

The explanatory report gives the following clarification: ‘The third paragraph prescribes that when an adult is not capable of consenting to an intervention, the intervention may be carried out only with the consent of his or her legal representative or any person or body provided for by law. Furthermore, the participation of adults not able to consent in decisions must not be totally ruled out. This idea is reflected in the obligation to involve the adult in the authorisation procedure whenever possible. Thus, it will be necessary to explain to them the significance and circumstances of the intervention and then obtain their opinion. According to paragraph 5, the person or body concerned may withdraw their authorisation at any time, provided that this is done in the interest of the person not able to consent. The first duty of doctors or other health care professionals is to their patient and it is also part of the professional standard (Article 4) to act in the interest of the patient. It is, in fact, a duty of the doctor to protect the patient against decisions taken by a person or body whose authorisation is required, which are not in the interest of the patient; in this respect, national law should provide adequate recourse procedures. The subordination of consent (or its withdrawal) to the interest of the patient is in keeping with the objective of protecting the person. While a person capable of giving consent to an intervention has the right to withdraw that consent freely, even if this appears to be contrary to the person's interest, the same right must not apply to an authorisation given for an intervention on another person, which should be retractable only if this is in the interest of that third party person. It was not considered necessary to provide in this article for a right of appeal against the decision of the legal representative to authorise or refuse to authorise an intervention. In the very terms of paragraphs 2 and 3 of this article, the intervention may be carried out only "with the authorisation of his or her representative or an authority or a person or body provided for by law", which in itself implies the possibility of appealing to a body or authority in the manner provided for in domestic law.’⁵⁶

⁵⁶ Explanatory Report to the Biomedicine Convention, §§45-49.

1.2.2.3 Article 9 – Previously expressed wishes

The Biomedicine Convention does not address advance directives as such, but acknowledges them indirectly as formulations of the ‘previously expressed wishes’ of the patient.⁵⁷

Article 9 provides 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’.

This is the first recognition of the legal value of advance directives in a European binding document.⁵⁸ The exact meaning of the expression ‘taken into account’ is the object of controversy. According to Adriano Bompiani, who was directly involved in the drafting of the Convention as Italian representative, this expression was adopted as a way to find a balance between, on the one hand, due consideration of the patient’s wishes expressed in advance, and on the other, a technical, objective assessment of the current clinical situation of the patient and of the elementary duties of the doctor to choose the more adequate treatment according to the current circumstances.⁵⁹ Andorno rightly states that although this compromise formula is understandable in the light of the conflicting views of European countries on this matter, and of the framework nature of the Biomedicine Convention, the wording of article 9 is problematic in the sense that the expression ‘taken into account’, without any additional clarification, is too ambiguous and can be interpreted in different ways.⁶⁰ It is not clear what is to be understood by ‘taking into account’ – i.e. what authority is to be accorded to an advance directive and what an advance directive may legitimately cover: it remains open whether the advance directive merely provides an indication of presumed wishes or whether it has a binding authority. It is also striking that article 9 refers to ‘previously expressed wishes’ instead of ‘advance directives’. This latter expression, which is used neither in the Convention itself nor in its Explanatory Report, was not included on the (mistaken) presumption that advance directives are always binding. The Explanatory Report has even reinforced the confusion on the meaning of ‘taken into account’. It only states that the expression ‘does not mean that previously expressed wishes should *necessarily* be followed’⁶¹ implying that previously expressed wishes are at least *prima facie* binding. This implication is reinforced by the example given in the Report: 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 spirit of article 9 is that doctors cannot act arbitrarily and need good reasons to disregard the patient’s previously expressed wishes.⁶²

⁵⁷ S.Lotjönen, ‘Medical research on patients with dementia – the role of advance directives in European legal instruments’, *European Journal of Health Law*, 2006, 242.

⁵⁸ R. ANDORNO, ‘Regulating advance directives at the Council of Europe’ in S.NEGRI, *Self-Determination, Dignity and End-of-Life Care. Regulating Advance Directives in International and Comparative Perspective*, Leiden-Boston, Martinus Nijhoff, 2011, 76.

⁵⁹ R. ANDORNO, ‘Regulating advance directives at the Council of Europe’ in S.NEGRI, *Self-Determination, Dignity and End-of-Life Care. Regulating Advance Directives in International and Comparative Perspective*, Leiden-Boston, Martinus Nijhoff, 2011, 76.

⁶⁰ R. ANDORNO, ‘Regulating advance directives at the Council of Europe’ in S.NEGRI, *Self-Determination, Dignity and End-of-Life Care. Regulating Advance Directives in International and Comparative Perspective*, Leiden-Boston, Martinus Nijhoff, 2011, 77.

⁶¹ Explanatory Report § 60-62 (emphasis added) .

⁶² R.ANDORNO, ‘Regulating advance directives at the Council of Europe’ in S.NEGRI, *Self-Determination, Dignity and End-of-Life Care. Regulating Advance Directives in International and Comparative Perspective*, Leiden-Boston, Martinus Nijhoff, 2011, 78.

Another shortcoming of article 9 is that it is exclusively focused on (positive and negative) instructional directives and ignores the other form that an advance directive may have: the proxy directive.⁶³

We conclude our discussion of the Biomedicine Convention and advance directives with the following remark. Article 27 of this Convention provides:

'None of the provisions of this Convention shall be interpreted as limiting or otherwise affecting the possibility for a Party to grant a wider measure of protection with regard to the application of biology and medicine than is stipulated in this Convention'.

If article 9 has to be understood in a way that an advance directive is not binding but only indicative, article 27 authorises states that have ratified the Convention to give patients a wider protection by providing that an advance directive is binding and has to be respected under certain conditions.

1.2.3.Recommendation (2009)11 on principles concerning continuing powers of attorney and advance directives for incapacity

Recommendation (2009) 11 is of great relevance regarding advance directives as it seeks to fill the two above mentioned gaps of the Biomedicine Convention (the vagueness of article 9 regarding the binding character of advance directives and the lack of regulation of continuing powers of attorney).⁶⁴

1.2.3.1 The main principles of Recommendation (2009)1165

Promotion of self-determination

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. In accordance with the principles of self-determination and subsidiarity, states should consider giving those methods priority over other measures of protection (principle 1). 'Incapacity' is limited to what might be termed 'factual incapacity' or, in some states 'mental incapacity', although the latter term is outdated and unpopular. Such incapacity might impair the ability of an adult to make decisions, assert and exercise rights and so forth. An extreme form is the incapacity of a person in a coma or in persistent vegetative state. Although severe dementia or a profound learning disability (formerly 'mental handicap') can cause substantial incapacity, many other conditions can cause various lesser degrees of incapacity. It is, however, fundamental that such factual or mental incapacity, never detracts from the adults' rights and status in law.⁶⁶ 'Legal capacity' is a term that encompasses the adult's rights and status themselves, rather than the ability to exercise and assert them. 'Legal incapacity' refers to the diminution by law of an adult's rights and status.⁶⁷

⁶³ R. ANDORNO, 'Regulating advance directives at the Council of Europe' in S.NEGRI, *Self-Determination, Dignity and End-of-Life Care. Regulating Advance Directives in International and Comparative Perspective*, Leiden-Boston, Martinus Nijhoff, 2011, 77.

⁶⁴ R. ANDORNO, 'Regulating advance directives at the Council of Europe' in S.NEGRI, *Self-Determination, Dignity and End-of-Life Care. Regulating Advance Directives in International and Comparative Perspective*, Leiden-Boston, Martinus Nijhoff, 2011, 78-79.

⁶⁵ Based on H.NYS, 'The growing significance of advance declarations of will as an expression of the autonomy of the patient in Europe' in A.VERBEKE (Eds.), *Confronting the frontiers of family and succession law. Liber amicorum Walter Pintens*, Cambridge, Intersentia, 2012, 1047-1064.

⁶⁶ Explanatory Memorandum to Rec (2009) 11, § 39.

⁶⁷ Explanatory Memorandum to Rec (2009) 11, § 40.



Continuing powers of attorney

States should consider whether it should be possible for a continuing power of attorney to cover economic and financial matters, as well as health, welfare and other personal matters, and whether some particular matters should be excluded (principle 3). Traditionally, powers of attorney refer to 'economic and financial matters' or use the terminology 'property and financial matters'. This has also been the case with continuing powers of attorney. Economic and financial matters may, *inter alia*, include paying for medical care and residential care or nursing home fees. In recent years, it has become more common to widen continuing powers to health, welfare and other personal matters. In accordance with the principle of self-determination, the person concerned makes decisions in such matters when he is still capable of doing so. When he becomes incapacitated, and if the power of attorney so provides, the attorney can make decisions for him or her. The powers might include a whole range of primarily non-economic decisions, for instance, right of access to personal (medical) information about the granter, arrangements needed for the granter to be given medical treatment, consenting to or refusing medical examination and treatment and complaints about the granter's care and treatment.⁶⁸ There are differences between economic powers on the one hand and personal powers on the other. The latter should not be used as long as the granter is capable of making such decisions himself. Therefore, a power of attorney about personal matters should be operable only during the granter's incapacity. As mentioned in principle 3, states should consider whether some particular matters should be excluded. Any such exclusion should be kept to a minimum. Certain national legislation contains a rule that some questions are of such a character that the attorney is not permitted to deal with them and that they are therefore excluded. Hence, some health issues may be excluded, as they may pose various problems.⁶⁹ For instance, in Belgium, Luxembourg and the Netherlands, the request for euthanasia may never be included in a power of attorney.

According to principle 4, the granter may appoint as attorney any person whom he considers to be appropriate. He may appoint more than one attorney and may appoint them to act jointly, concurrently, separately, or as substitutes. States may consider such restrictions as are deemed necessary for the protection of the granter. The granter's choice of attorney is crucial to the success of the power of attorney. It is important that the granter considers the person or persons whom he wishes to appoint as appropriate. The granter should have confidence in the appointed person(s), as he will be unable to control the attorney's decisions, to appoint a new attorney, or to revoke the power of attorney when he becomes incapacitated. The appointed person(s) must be relied upon to take care of the interests of the granter. If these conditions are not fulfilled, there is a risk that the power of attorney will not function properly. A family member may often be preferred by the granter, but he may also wish to appoint his lawyer, notary, accountant, or simply a friend.⁷⁰

The form of the continuing power of attorney is dealt with in principle 5. A continuing power of attorney shall be in writing. Principle 5 is supplemented by principle 8, which concerns certification, registration and notification. According to the explanatory memorandum, it should be considered whether professional assistance should be recommended or even made compulsory while making up a continuing power of attorney. In some national legislation, there is a requirement that a professional, such as a lawyer or a notary assists, at least if the decision covers more important matters, for example major medical treatment. This implies that the granter has been duly informed about the consequences of the document and the possibility of revocation.⁷¹ This possibility to revoke the continuing power of attorney at any time is provided for in principle 6 of the

⁶⁸ Explanatory Memorandum to Rec (2009) 11, § 86-87.

⁶⁹ Explanatory Memorandum to Rec (2009) 11, § 94.

⁷⁰ Explanatory Memorandum to Rec (2009) 11, § 96.

⁷¹ Explanatory Memorandum to Rec (2009) 11, § 110.

recommendation. Termination of the continuing power of attorney during the granter's incapacity is dealt with in principle 13.

Principle 7 regards the entry into force of a continuing power of attorney. States should regulate the manner of entry into force of the continuing power of attorney in the event of the granter's incapacity. States should consider how incapacity should be determined and what evidence should be required. According to the explanatory memorandum, those procedures must protect the confidentiality of the detailed medical information upon which incapacity is certified, if such certification is required. Also, application of the principle of self-determination might allow the granter to decide himself what kind of evidence about his health situation shall be produced, whether or not it is the intent of the legislator that there should be any public involvement. In those countries where it exists, a medical certificate about the condition of the granter normally will be necessary and sufficient. There might be a provision, in the legislation or in the document, that the attorney has a right to obtain such a certificate regardless of the rules on professional confidentiality.⁷²

As already said, the entry into force of a continuing power of attorney shall not as such affect the legal capacity of the granter. This is confirmed in principle 9. As a consequence, a continuing power of attorney that can only be exercised in the event of the granter's incapacity, which is the case for a continuing power of attorney about health matters, may not be operated during periods when the granter has regained capacity.⁷³

According to principle 10.1, the attorney has to act in accordance with the continuing power of attorney and in the interests of the granter. The explanatory memorandum clarifies that acting in the interests of the granter means that decisions should be in accordance with what the granter, if capable, would have decided, in so far as this can reasonably be ascertained.⁷⁴ Principle 10.2 provides that as far as possible, the attorney informs and consults the granter on an ongoing basis while principle 10.3 states that the attorney, as far as possible, ascertains and takes account of the past and present wishes and feelings of the granter and gives them due respect. Such past wishes are especially mentioned in principle 10 because advance directives (see below) may be addressed to an attorney to whom a continuing power of attorney is granted.⁷⁵ In principle 10.4 it is stated that the attorney keeps sufficient records about dealings and transactions made under the power. The extent of the duty to keep a file of the paperwork depends on the nature of the mandate, and must be proportionate. In the case of a power of attorney about health, welfare and other personal matters, major decisions must be recorded. It may be useful to make notes on a regular basis. One reason for the requirement to keep records is that the attorney must be able to demonstrate the proper exercise of his mandate.⁷⁶

States should consider regulating conflicts of the granter's and the attorney's interests (principle 11). A basic concern is that continuing powers of attorney be used in accordance with the granter's intention and in his or her interests, as mentioned in principle 10.1. The starting point is that the decision to appoint a trusted attorney and to confer upon him power to act is a calculated risk taken by a capable granter, with the result that the attorney is allowed, as a rule, to do whatever he decides within the scope of the powers conferred. The granter should, at time of signing, be informed and aware of the fact that the attorney will act without automatic supervision. He might well see it as an advantage that public authorities are not involved. On the other hand, it can be pointed out that the risk of misuse may be overestimated, and that the same risk might exist without


⁷² Explanatory Memorandum to Rec (2009) 11, § 123-126.

⁷³ Explanatory Memorandum to Rec (2009) 11, § 146.

⁷⁴ Explanatory Memorandum to Rec (2009) 11, § 148.

⁷⁵ Explanatory Memorandum to Rec (2009) 11, § 150.

⁷⁶ Explanatory Memorandum to Rec (2009) 11, § 152-153.



a document. An essential feature of a continuing power of attorney is therefore that public authorities are not automatically and routinely involved in supervising all actions of the attorneys.⁷⁷ However, according to principle 12.1 the granter may establish himself a private supervision system. The purpose of privately-organised supervision is to ensure that the attorney takes proper care of the interests of the granter, that he does not act in situations where there is a potential conflict of interests, and that there is no misuse.⁷⁸ Moreover, according to principle 12.2 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. Such intervention might include terminating the continuing power of attorney in part or in whole. The competent authority should be able to act on request or on its own motion. The point at which a need for public supervision arises depends on the nature of the problem. Supervision is probably necessary in case of risk of misuse of the power. The attorney may also have shown himself to be unable to perform the task. A particular problem is whether the power should be terminated in case of conflicts between the attorney and close family members about what is in the granter's interest. It is probably not sufficient that the relatives are simply dissatisfied with the attorney or his performance, as long as he takes care of the interests of the granter, according to the provisions of the document.⁷⁹ It is left to states to determine the circumstances under which the power of attorney should be terminated (principle 13).

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 (principle 14). Health issues are mentioned first here, as there is a need for careful regulation in this area. Such directives may or may not be addressed to particular persons such as representatives appointed by a competent authority but also to an attorney, medical staff or other persons who make decisions on behalf of or affecting the author during incapacity. They are always unilateral documents which do not establish a contract with any such person.⁸⁰

Principle 2.3 defines advance directives as 'instructions given or wishes made by a capable adult concerning issues that may arise in the event of his or her incapacity'. The use of both terms (instructions and wishes) is no coincidence: the word 'instructions' is employed to refer to advance directives that are legally binding while 'wishes' is used to indicate that such documents have a merely advisory value.⁸¹ This double terminology shows well the deep disagreement between European countries concerning the legal effect to be given to advance directives.⁸² The question of the binding or not binding effect of the advance directives should, as mentioned in principle 15.1, be addressed in legislation. Advance directives which do not have binding effect should, according to the same principle, be treated as statements of wishes to be given 'due respect'. Interestingly, the terminology used in principle 15 to refer to previously expressed wishes is slightly different from the one used in article 9 of the Biomedicine Convention. While this article provides that these wishes shall be 'taken into account' (see above), principle 15 of the recommendation stipulates that they should be given 'due respect'. According to Andorno, the latter wording sounds stronger than the one of the Biomedicine Convention. Having respect seems to imply the binding character of an

⁷⁷ Explanatory Memorandum to Rec (2009) 11, § 160.


⁷⁸ Explanatory Memorandum to Rec (2009) 11, § 161.

⁷⁹ Explanatory Memorandum to Rec (2009) 11, § 163.

⁸⁰ Explanatory Memorandum to Rec (2009) 11, § 176-177.

⁸¹ Explanatory Memorandum to Rec (2009) 11, § 178.

⁸² R. ANDORNO, 'Regulating advance directives at the Council of Europe' in S.NEGRI, Self-Determination, Dignity and End-of-Life Care. Regulating Advance Directives in International and Comparative Perspective, Leiden-Boston, Martinus Nijhoff, 2011, 84.



advance directive. Whether this difference in wording is deliberate or simply an oversight is not clear. But the latter is more likely since it only appears in the English version of the recommendation, while the French text employs the same expression that is used in article 9: ‘*prendre en compte*’, that is ‘*take into account*’.⁸³ Nevertheless, the recommendation goes a step further by explicitly recognizing the validity of a binding advance directive. However, according to principle 15.2, it is also important to regulate through legislation situations that arise in the event of a substantial change in circumstances. Examples might include cases where, since the advance directive was issued, a medical procedure prohibited by the advance directive has been much improved so that it is less hazardous, or less intrusive, or there has been a substantial change in family circumstances. This is especially necessary if the advance directive is binding.⁸⁴

Advance directives may be made in writing or may be expressed orally to family members, medical staff or others. According to principle 16.1, states should consider whether all or certain types of advance directives should be made or recorded in writing if intended to have binding effect. It is also important that the principle of self-determination is not impaired by doubts about validity of an advance directive. States should therefore, as stated in principle 16.2, consider what other provisions and mechanisms may be required to ensure the validity and effectiveness of those advance directives, mentioned in 16.1. If a directive is about health issues, it is advisable that the adult receives guidance from a lawyer, a notary or a medical doctor in order to ensure that the directive is clear and that the adult is aware of the consequences of the choice.⁸⁵

An advance directive is of no value if it is not known by or accessible to persons who need to make decisions on behalf of or in relation to the incapacitated adult. A general consideration is whether there should be an obligation to enter some, or all, advance directives into a public register, or whether this should be done on a voluntary basis. It might consequently be necessary to establish who should have access to such a register, especially bearing in mind data protection legislation.⁸⁶

Principle 17 states that it should be possible to revoke an advance directive at any time and without formalities. This can be done even if the directive is binding and as long as the adult is capable of making the decision on revocation. A capable person with severe physical disability may be able to revoke orally or by an unequivocal gesture only.⁸⁷

The recommendation does not bring to an end the lack of consensus between the European countries regarding advance directives. States are still left to decide whether advance directives should be legally binding or not. This does not mean that no progress has been made in this field since the Biomedicine Convention. Today, there is a growing awareness of the importance of enhancing patient’s self-determination and avoiding futile or disproportionate treatments.⁸⁸ The recommendation has also been welcomed because it has drawn the attention of European states to

⁸³ R. ANDORNO, ‘Regulating advance directives at the Council of Europe’ in S.NEGRI, *Self-Determination, Dignity and End-of-Life Care. Regulating Advance Directives in International and Comparative Perspective*, Leiden-Boston, Martinus Nijhoff, 2011, 84-85.

⁸⁴ Explanatory Memorandum to Rec (2009) 11, § 180.

⁸⁵ Explanatory Memorandum to Rec (2009) 11, § 183.

⁸⁶ Explanatory Memorandum to Rec (2009) 11, § 184.

⁸⁷ Explanatory Memorandum to Rec (2009) 11, § 186.

⁸⁸ R. ANDORNO, ‘Regulating advance directives at the Council of Europe’ in S.NEGRI, *Self-Determination, Dignity and End-of-Life Care. Regulating Advance Directives in International and Comparative Perspective*, Leiden-Boston, Martinus Nijhoff, 2011, 84.

an alternative and less controversial tool for planning health care in advance than instructional advance directives: the continuing power of attorney.⁸⁹

1.2.4. Resolution 1859 (2012) and Recommendation 1993 (2012) of the Parliamentary Assembly of the Council of Europe on protecting human rights and dignity by taking into account previously expressed wishes of patients.

On 25 January 2012 resolution 1859 (2012) and recommendation 1993 (2012) have been adopted by the Parliamentary Assembly of the Council of Europe. Principle 1 of the resolution stipulates that there is a general consensus, based on article 8 of the ECHR on the right to privacy 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. 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 the resolution. Council of Europe standards in this field should be developed further in accordance with these principles. Therefore 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.


Resolution 1859 (2012) recommends that member states:

- 6.1. Sign, ratify and fully implement the Biomedicine Convention, if they have not already done so;
- 6.2. Apply Recommendation Rec (2009)11 on principles concerning continuing powers of attorney and advance directives for incapacity;
- 6.3. Review, if need be, their relevant legislation with a view to possibly improving it:
 - 6.3.1. 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 Biomedicine Convention and Recommendation 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;
 - 6.3.2. 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.

The Parliamentary 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 Biomedicine Convention and Recommendation Rec(2009)11:

- 7.1. 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;
- 7.2. 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);
- 7.3. 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;

⁸⁹ R. ANDORNO, 'Regulating advance directives at the Council of Europe' in S.NEGRI, Self-Determination, Dignity and End-of-Life Care. Regulating Advance Directives in International and Comparative Perspective, Leiden-Boston, Martinus Nijhoff, 2011, 85.

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- 7.4. Advance directives, living wills and/or continuing powers of attorney should be accessible to all; thus, complicated forms or expensive formalities should be avoided;
- 7.5. 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;
- 7.6. 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.

2. The legal status of advance directives in the EU member states

2.1 The consequences of the ratification of the Biomedicine Convention on the legal status of advance directives in the ratifying states

Whatever the exact meaning of article 9 of the Biomedicine Convention, States that have ratified the Biomedicine Convention have to recognize at least the indicative value of previously wishes expressed in advance directive. Ratification of an international treaty such as the Biomedicine Convention has important legal consequences. Article 1 § 2 of the Biomedicine Convention clearly imposes the responsibility for the development and effective implementation of the Convention's norms upon the States that have ratified it. In other words: the internal law of the States that have ratified the Convention has to conform to the Convention. In this respect it is clarifying to cite the Explanatory Report to the Convention: 'Conformity between the Convention and domestic law may be achieved by either applying directly the Convention's provisions in domestic law or by enacting the necessary legislation to give effect to them. With regard to each provision (of the Convention), the means will have to be determined by each Party in accordance with its constitutional law and taking into account the nature of the provision in question. In this respect, it should be noted that the Convention contains a number of provisions which may under the domestic law of many States qualify as directly applicable ('self-executing provisions').⁹⁰ In other words, conformity of internal law with the provisions of the Convention does not necessarily imply that existing national legislation has to be adapted or new national legislation should be enacted. There is a general agreement that article 9 of the Biomedicine Convention is directly applicable. This means in practice that an advance directive becomes legally valid in a country that has ratified the Biomedicine Convention even if there is no specific regulation of advance directives in that country. This conclusion mitigates the principle importance of the distinction between countries that dispose of specific legislation of advance directives and those that do not dispose of such legislation but have ratified the Biomedicine Convention. Table 1 gives an overview of the status of the Biomedicine Convention in the member states of the EU without specific legislation on advance directives.

⁹⁰ Explanatory Report § 20.

TABLE 1. EU Member states without specific legislation regarding advance directives

COUNTRY	BIOMEDICINE CONVENTION RATIFIED OR NOT
1. Bulgaria	Yes (in 2003)
2. Cyprus	Yes (in 2001)
3. Czech Republic	Yes (in 2001)
4. Greece	Yes (in 1999)
5. Ireland	No
6. Italy ⁹¹	No
7. Lithuania	Yes (in 2003)
8. Malta	No
9. Poland	No
10. Romania	Yes (in 2001)
11. Slovakia	Yes (in 1999)
12. Sweden	No

Seven of these countries have ratified the Biomedicine Convention. Given the direct applicability of article 9 of this Convention, the legal validity of advance directives in these countries is beyond any discussion. If we also take into consideration the countries where specific legislation of advance directives already exists (see table 2, below) this means that the legal validity of advance directives is recognised in 22 Member States of the EU. Moreover, 2 of the 5 countries without specific legislation and that not yet ratified the Biomedicine Convention are in a process of approving specific legislation: Ireland⁹² and Italy⁹³.

In this regard it is noteworthy to mention that in a resolution on the situation of fundamental rights in the Union, the European Parliament invited all Member States lacking a specific legislation on advance directives to adopt such laws as necessary:

*‘to ensure that, according to article 9 of the Oviedo Convention on human rights and biomedicine, “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” and to ensure the right to dignity at the end of life’.*⁹⁴

We can conclude that advance directives are lawful in the great majority of EU member states in one or another way. Moreover there is clearly an ‘absence of a European consensus against advance directives’.⁹⁵ None of the countries without specific legislation on advance directives and that did not ratify the Biomedicine Convention have prohibited advance directives.

⁹¹ Italy has approved the Biomedicine Convention by law 145 of 28 March 2001, published in the Gazzetta Ufficiale n.95 of 24 April 2001 but has not yet deposited the instrument of ratification of the Convention on human rights and biomedicine so that the Convention is not ratified by Italy.

⁹² P.HANAFIN, ‘End-of-life decision-making in contemporary Ireland’ in S.NEGRI, *Self-Determination, Dignity and End-of-Life Care. Regulating Advance Directives in International and Comparative Perspective*, Leiden-Boston, Martinus Nijhoff, 2011, 209-219.

⁹³ Italian draft bill on ‘dispositions in matter of therapeutic alliance, informed consent and advance treatment directive’ in S.NEGRI, *Self-Determination, Dignity and End-of-Life Care. Regulating Advance Directives in International and Comparative Perspective*, Leiden-Boston, Martinus Nijhoff, 2011, 455-460.

⁹⁴ European Parliament, Resolution of 14 January 2009 on the situation of fundamental rights in the European Union 2004-2008, *Official Journal of the European Union*, C 46E/08, 24 February 2010, p.48-69, § 167.

⁹⁵ P.LEWIS, ‘Medical treatment of dementia patients at the end of life’, *European Journal of Health Law*, 2006,232.


2.2 The legal status of advance directives in EU Member states with specific legislation on advance directives

a) Introductory remark

There is striking contrast between the decades-long attention paid to advance care planning in the United States and the only recent interest given to it in Europe. In the U.S., the public debate about the scope and legal validity of advance directives started around thirty years ago. In contrast the legal attention given to advance directives in most European countries is very recent. Table 2 gives an overview of the member states of the European Union that already have approved specific laws regulating advance directives.

Tabel 2. EU Member States with specific legislation regarding advance directives

COUNTRY	YEAR OF LAW	CONVENTION BIOMEDICINE RATIFIED OR NOT
1. <i>Austria</i>	2006	No
2. <i>Belgium</i>	2002	No
3. <i>Denmark</i>	1998	Yes (1999)
4. <i>Estonia</i>	2001	Yes (2002)
5. <i>Finland</i>	2005	Yes (2010)
6. <i>France</i>	2005	Yes (2012)
7. <i>Germany</i>	2009	No
8. <i>Hungary</i>	2009	Yes (2002)
9. <i>Latvia</i>	2009	Yes (2010)
10. <i>Luxembourg</i>	2009	No
11. <i>Netherlands</i>	1994	No
12. <i>Portugal</i>	2012	Yes (2001)
13. <i>Slovenia</i>	2007	Yes (1999)
14. <i>Spain</i>	2002	Yes (2000)
15. <i>United Kingdom</i>	2005	No



Ten of the 15 laws have been approved after 2005. Only 2 (the Danish and the Dutch law) have been approved before 2000. The relative recent character of advance directives in European countries may at least partially explain the lack of empirical data concerning the use that is made of advance directives in practice. As far as figures are available (see below), they all confirm what is stated in principle 4 of Resolution 1859 (2012) of the Council of Europe: '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 the previously expressed wishes into account, and thus effectively protect their human rights and dignity'.

b) Austria

Advance directives are regulated by the Federal Act of 8 May 2006 on advance directives.⁹⁶ Section 1(2) of the act stipulates that an advance directive may either be binding, or must be taken into account when establishing the patient's will. According to section 2 (1) an advance directive in the sense of the act is a declaration of will, by which a patient refuses a medical treatment and which shall become effective if the patient is unable to understand, judge or express himself at the moment of the treatment.

Legal conditions for a binding advance directive

- Clearly described content

In a binding advance directive the medical treatments which are the object of refusal, must be concretely described or unambiguously emerge from the overall context of the advance directive. Additionally, it must be evident from the advance directive that the patient appropriately evaluates the consequences of the advance directive (section 4).

- Formal aspects

The patient has to consult a qualified physician who has to inform him about the nature and the consequences of his advance refusal and who evaluates the patient's capacity to insight and judgment concerning the refused medical interventions as well as for which reasons the patient appropriately evaluates the consequences of the advance directive. This had to be documented and confirmed by the informing physician in the advance directive (section 5). Only hereafter the advance directive may be drafted by an attorney, notary or legally trained associate of the patients' advocacies (representatives) (section 6)

A binding advance directive will lose its validity, if the patient revokes it itself or shows by his behavior that it is no longer valid. In addition, an advance directive is invalid if it is not based on a free and well-considered declaration of will, if it has been initiated by error, fraud, deception or by physical or mental pressure or if its content is legally unacceptable. An advance directive will also lose its validity if the standard of medical science regarding the content of the advance directive has essentially changed in the meantime (section 10).

- Validity in time

A binding advance refusal generally loses its binding character five years after its drafting, unless a shorter expiry date is fixed. A renewal is possible under the requirements mentioned above. It may be pointed out that the binding advance directive may be prolonged until the patient is able to renew it, if the patient loses his ability to understand, judge or express himself during the term of

⁹⁶ Patientenverfügungsgesetz – PatVG, published in the Federal Law Gazette of the Republic of Austria of 8 May 2006. See the English version of the act on www.patientenanwalt.com. See also, A. Leischner, C. Zeinhofer, C. Lindner and C. Kopetzki, 'Austria' in H.NYS (ed), *International Encyclopaedia of Laws. Medical law*, Wolters Kluwer, Alphen ad Rijn, 2011, 89-91.

validity of the binding advance directive (section 7). In other words, once the patient has become incompetent the advance directive is valid for an unlimited period of time.

- *Documentation and registration*

The advance directive has to be documented by the informing and the attending physician in the patient's medical record (section 14). The Austrian law has not stipulated an obligatory documentation in a central register. As a result the patient has the duty to notify the attending physician of the existence and the content of the advance directive. If the patient is unable to do so in advance, the attending physician shall take reasonable efforts to check whether the patient has drawn up an advance refusal or not, for instance by asking his relatives or by accessing his medical records. If the time spent on searching an advance directive seriously endangers the patients' life or health, the attending physician is no longer obliged to search for an advance directive. Instead he has to provide the required emergency medical treatment (section 12).

The non-binding advance directive

An advance directive which does not fulfill all conditions mentioned in sections 4 to 7, must nevertheless be taken into account for the establishment of the patient's will (section 8). The more a non-binding advance directive fulfills the requirements of a binding advance directive, the more it shall be taken into account for the establishment of the patient's will. Thereby, it shall be considered in particular to what extent the patient was able to evaluate the disease situation, which the advance directive is related to, as well as the consequences of it at the time of drawing up the advance directive, how concretely the medical treatments which are the object of refusal, are described, how comprehensive the medical information prior to the execution was, to what extent the advance directives deviates from the formal requirements of a binding advance directive, how often the advance directive was renewed and how far back the most recent renewal dates (section 9).

Durable power of attorney in health matters⁹⁷

Since July 2007, the Austrian civil code provides the legal institute of the health care proxy (§ 284f ABGB (Austrian Civil Code; *vorsorgevollmacht in Gesundheitsangelegenheiten*)). Every person with full legal capacity may grant a durable power of attorney regarding concretely defined affairs to a person of particular confidence. He can either choose to grant a health care proxy for giving consent to medical treatment or instruct the attorney to make sure that his refusal of specified medical treatments is respected. However, the validity of latter instructions is subject to the prerequisites of the Federal Act on advance directives. Since medical decisions do not require full legal capacity, but merely capacity to insight and judgment, it is generally acknowledged that also a minor and mentally ill patients who are capable of understanding, judging and expressing their will, can appoint a health care proxy.

As to legal representation concerning simple medical matters of everyday life, the health care proxy has to be set up in form of a testament. Therefore it has to be manually written and signed by the person granting the authority. If the principal only signs the document, three unbiased witnesses who have full legal capacity and are proficient in the language the document was written in have to confirm that the content of the health care proxy fully corresponds to the principal's intentions. If the principal does not sign the health care proxy, its content has to be confirmed by a notary (§ 284f[2] Austrian Civil Code). Concerning legal representation in serious medical matters, the health care proxy has to be drawn up before a lawyer, notary or judge and shall explicitly name the respective

⁹⁷ Based on A. Leischner, C.Zeinhofer, C.Lindner and C.Kopetzki, 'Austria' in H.NYS (ed), *International Encyclopaedia of Laws.Medical law*, Wolters Kluwer, Alphen ad Rijn, 2011, 91-92.

medical matters. The lawyer, notary or judge has to inform the principal about the consequences of the health care proxy, the possibility of revocation at any time and has to confirm the provision of this instruction by indicating his name and address and personally signing the document (§ 284f[3] Austrian Civil Code). The health care proxy becomes effective as soon as the patient becomes unconscious or unable to make medical decisions due to incapacity of insight and judgment or inability to express these. The health care proxy's coming into effect has to be registered by the Austrian Register of Representation.

It may be pointed out, that the health care proxy is the unique case in Austrian law, in which a third party might be obliged to take care that a medical intervention is not performed or discontinued on behalf of the patient's unambiguous declaration of will, even though the decision of the third party might be against the patient's well-being from an objective point of view (§284h[1] Austrian Civil Code).

Representation by the relatives⁹⁸

The possibility of representation by close relatives is regulated in §§ 284 b-e Austrian Civil Code. The close relative can now give his or her consent to medical treatment to the extent that this usually does not lead to a serious or lasting detriment to the physical integrity or personality of the patient and the latter lacks the required ability to comprehend and to judge. Close relatives are parents, full age children who live in the same household as the represented person, spouse and co-habiting partners if they have lived with the patient for at least three years. The close relative has to have his/her entitlement to represent registered in the Austrian Central Register of Representatives prior to the execution of the representation. A doctor can rely on the entitlement to represent if the close relative submits the confirmation of the registration. The relative entitled to represent the patient will promote the well-being of the represented individual to the best of his/her ability and seek to ensure that the patient can organise his/her life in accordance with his/her wishes, taking their abilities and possibilities into account. If an advance directive exists, the relative entitled to represent has to abide by the wishes stated therein. If several relatives are entitled to represent the patient, the assent of one person is sufficient. If contradictory declarations exist, none is valid. The representation authorization is not valid or ends if the represented patient – regardless of whether able to comprehend or make a judgment – has objected or objects to it.

Implementation of advance directives in practice⁹⁹

Less than 5% of hospital patients have drafted an advance directive. So far no exact numbers have been published. Less than 3000 (<1%) fully binding advance directives are known (combination of statistical databases). In Austria, 5,155 registrations were made from the entry into force of the new legislation on 1 July 2007 to October 2008.¹⁰⁰

c) Belgium¹⁰¹


The rights and duties of physicians and patients are regulated in the law on the rights of patients of 22 August 2002. Patients have the right to refuse or withdraw their consent for any intervention

⁹⁸ Based on J.Inthorn and M.Kletecka-Pulker, 'Austria' in *Advance directives: towards a coordinated European perspective*, Zürich, Institute for Biomedical Ethics, June 2008, p.6-7

⁹⁹ J.Inthorn and M.Kletecka-Puckel, 'Austria' in *Advance directives: towards a coordinated European perspective*, Zürich, Institute for Biomedical Ethics, June 2008, p.8.

¹⁰⁰ Explanatory Memorandum to Rec (2009) 11 § 30.

¹⁰¹ Based on H.Nys, 'Belgium' in H.Nys (ed), *International Encyclopaedia of Laws. Medical law*, Wolters Kluwer, Alphen ad Rijn, 2012.



(Article 8, 4°, §1 of the law on patient rights). If the patient has made a written statement refusing a specific medical intervention at the time when he was still capable of asserting the rights covered in the law on the rights of patients, this refusal shall be respected as long as the patient does not revoke it in a period when he or she is competent to exercise his or her rights himself or herself (Article 8, 4°, §4). Although the notion 'advance directive' is not used by the law, it clearly envisages this. Positive advance directives are not covered by this law.

Legal conditions for a binding advance directive

- *Refusal of a specific medical intervention*

The law requires the refusal of a specific medical intervention in order that the advance directive has to be respected. Otherwise it has to be taken into account.

- *Formal aspects*

In order to be binding the advance refusal has to be written. There are no other formal requirements such as presence of a witness, etc.

To draft an advance directive one has to have the capacity to assert the rights of the patient. No evaluation of the capacity at the moment of drafting the advance directive nor an obligation to be counseled by a physician are provided for.

- *Validity in time*

The law does not provide for a limitation of the validity in time. In principle the advance directive is valid irrespective of when it has been written. However, as time passes it is possible that there exist medical alternatives for the specific medical intervention which is refused in an advance directive. Although the law does not allow physicians explicitly not to follow an advance directive when the circumstances have been changed, in practice this may be the case for older advance directives.

- *Documentation and registration*


At the request of the patient, the health professional adds any documents supplied by the patient to his medical records (Article 9, 1°, §2 law on patient rights, for instance an advance directive drafted by the patient). There is no official registration system. It is up to the patient and/or his representative (see below) to assure that the advance directive is known and available to the treating physicians. In an emergency situation a physician will often not have enough time to verify this and his duty to provide assistance will take precedence (article 8 §5 of the law on patient rights).

Durable power of attorney in health matters

The rights of adult patients who are not capable of exercising their rights as a patient are exercised by the person previously designated by said patients to act on their behalf when and for as long as they are unable to exercise these rights themselves. This so-called *patient-designated representative* has to be designated using a specific written mandate, dated and signed by the patient and by this person, clearly showing the latter's consent. Patients or patient-designated representatives may always revoke this mandate (Article 14, §1 of the law on patient rights).

Representation by the relatives

If there is no patient-designated representative or if he fails to act, the rights of the incapable adult patient can be exercised by the cohabiting spouse, the legally cohabiting partner, or the actual cohabiting partner. If this person refuses or if there is no such person, the rights can be asserted, in



descending order, by an adult child, a parent, or an adult brother or sister of the patient. If these persons refuse or if there are no such persons, the health professional concerned has to take care of the patient's interests, possibly after multidisciplinary consultation. This is also the case when there is a conflict between two or more representatives of equal rank, for instance a conflict between two children of the patient (Article 14, §2 of the law on patient rights). A health professional, possibly after multidisciplinary consultation, has an obligation to deviate from the decision taken by the legal representative of the patient, in the interest of the patient, to avert a threat to the patient's life or serious damage to his health. However, when the decision was taken by a so-called patient-designated representative, the health professional may deviate from this decision only insofar as this representative is unable to refer to the patient's express will, such as an advance refusal of a life-saving treatment (Article 15, §2 of the law on patient rights).

d) Denmark¹⁰²

In 2005 the Danish Parliament adopted the Health Act - Law No. 546 of 24 June 2005 – putting together different acts related to patient rights, especially Law No. 482 of 1 July 1998 on patient rights and a number of other acts which contain patient rights provisions. The new act on patient rights has come into force on 1 January 2007. Most of the provisions in the new act are similar to the provisions contained in the previous acts including the Patient Rights Act of 1998. There is no general rule in Danish law regarding previously expressed wishes. Has a person, at an earlier stage – but not in connection with an actual treatment – expressed his attitude to treatment (a positive advance declaration) or to avoid treatment (a negative advance declaration), this will only be informative for the health care provider, and these wishes are only an element to be considered when deciding how to treat the patient.¹⁰³ Also the competent closest relatives (see below) are in no way bound to follow these wishes.¹⁰⁴

Legal conditions for a binding advance directive

Only for specific situations the Health Act 2005 contains rules regarding the binding effect of previously expressed wishes. Section 1 of § 26 of the Health Act 2005 provides that any person over the age of 18 and not under guardianship may establish an advance directive. In the advance directive the patient may express his wishes regarding treatment, in case he experiences a condition where he is no longer able to perform his right to self-determination.

- *Only refusal of life prolonging treatment*

According to section 2 of the Health Act it is possible to record in an advance directive conditions regarding:

- a) refusal of life prolonging treatment in situations where the patient is terminally ill, and
- b) refusal of life prolonging treatment in case of illness, progressed decrepitude, accident, heart failure or the like leaving the patient permanently unable to take care of himself or herself physically and mentally.

Life prolonging treatment is defined in section 3 as treatment with no prospect of cure, improvement or relief, but only for some life prolonging. It does not include life-supporting treatment.

According to section 5 the wishes expressed according to section 2 (a) (terminally ill patient refusing life prolonging treatment) are binding for the health care provider who in other words is obliged to respect the patient's request to omit treatment. The law requires that solely the assessment of the

¹⁰² Based on H.NYS, et al., 'Patient Rights in the EU – Denmark', European Ethical-Legal Papers, N° 2, Leuven, 2007.

¹⁰³ U.HYBEL, 'Country Report Denmark', in J.TAUPITZ, Regulations of civil law to safeguard the autonomy of patients at the end of their life, Berlin, Springer, 2000, 504.

¹⁰⁴ U.HYBEL, 'Country Report Denmark', in J.TAUPITZ, Regulations of civil law to safeguard the autonomy of patients at the end of their life, Berlin, Springer, 2000, 504.

patient's medical condition may be taken into consideration, whereas other factors may not be given relevance, e.g. the physician's personal preferences, research interests or economic motives.¹⁰⁵

- Formal aspects

A clear statement issued in a different manner may be given legal status equivalent to an advance directive filed on the official formula, if a physician becomes aware of its existence and content.¹⁰⁶ A patient may always revoke the living will by issuing a written and clear notification to the Registry. The advance directive may informally be revoked by a plain statement, e.g. to the responsible physician or another health care professional.¹⁰⁷

- Validity in time

The validity of an advance directive is not limited to a set period of time.¹⁰⁸

- *Documentation and registration*

Section 26 (4) stipulates that in case a health care provider, when the patient is unable to perform his right to self-determination, is planning the initiation of life prolonging treatment to a terminally ill patient, or plans on continuing life prolonging treatment in a situation as described in section 2 (b), he must contact the living will registry established according to section 27 to check for the existence of an advance directive. Section 27 (1) empowers the Interior and Health Minister to establish an advance directives register and determine regulations for the issue, design, registration and withdrawal of living wills. The registration procedure currently costs about 7 €.

The non-binding advance directive

A wish expressed according to section 2 (b) of the Health Act (permanently severely impaired patient refusing life prolonging treatment) is only a recommendation for the health care provider and must be taken into consideration as such. The law presupposes that the request in such an advance directive, although legally not binding, may only be overruled due to reasons of a very substantial nature. In the physician's considerations, a number of factors might be included, e.g. the nature and progression of the illness, the treatment options, the patient's age and life situation, the relatives' opinions etc. The physician's discretionary power in this respect is rather wide and vague.¹⁰⁹

Durable power of attorney in health matters

In this respect it is important to remark that the patient cannot formally and with a binding effect appoint the closest relative or another person whom he wants to have his decision making capacity in connection with future treatment, but it must be supposed that great importance will be attached to the patient's opinion on this – to the extent that his wishes are known.¹¹⁰

Section 14 of the Health Care Act 2005 states: 'For a patient unable to represent himself the patient rights are transferred to the person(s) authorized to represent the patient when required to represent the patient's interest in the actual situation'. A representative for the incompetent patient can be appointed in accordance with the rules of the Guardianship Act of 14 June 1995. This act contains rules on the support and protection of adults who are incapable of fully taking care of themselves. In cases where the patient is under guardianship concerning personal affairs, health issues included, the informed consent may be provided by the guardian. It must be supposed that

¹⁰⁵ J.VESTERGAARD, 'Medical aid in dying under Danish law', *European Journal of Health Law*, 2000, 415.

¹⁰⁶ J.VESTERGAARD, 'Medical aid in dying under Danish law', *European Journal of Health Law*, 2000, 416.

¹⁰⁷ J.VESTERGAARD, 'Medical aid in dying under Danish law', *European Journal of Health Law*, 2000, 416.

¹⁰⁸ J.VESTERGAARD, 'Medical aid in dying under Danish law', *European Journal of Health Law*, 2000, 415; for more details about the Register, see also this article and U.HYBEL, 'Country Report Denmark', in J.TAUPITZ, *Regulations of civil law to safeguard the autonomy of patients at the end of their life*, Berlin, Springer, 2000, 509-510.

¹⁰⁹ J.VESTERGAARD, 'Medical aid in dying under Danish law', *European Journal of Health Law*, 2000, 416.

¹¹⁰ U.HYBEL, 'Country Report Denmark', in J.TAUPITZ, *Regulations of civil law to safeguard the autonomy of patients at the end of their life*, Berlin, Springer, 2000, 505.

when a patient has a guardian, it is the guardian and not the closest relative who is authorized to give consent.¹¹¹ However, by far the greater number of the patients who are found to be incompetent regarding treatment issues do not have a guardian.

Representation by the relatives

Section 18 (1) stipulates that for a patient who is permanently unable to provide informed consent, the closest relative can provide informed consent to treatment. The act itself does not define who belongs to the group of closest relatives, but according to the parliamentary preparatory documents the group is to be defined in each case individually. First and foremost come the patient's cohabiting partner or spouse, direct descendants, and depending on the actual circumstances, siblings. Other relatives who the patient is close to may, in some circumstances, also be considered close relatives, especially in cases where there are no cohabiting spouse, partner or children. It also appears that family ties are not always decisive. A close friend or care worker may be included if it is certain that the patient regards that person as 'closest relative'.¹¹²

It cannot be excluded that 'a group of relatives disagree on the treatment question'.¹¹³ Danish law does not contain a rule to offer a solution in case of disagreement among relatives.

If a patient who is permanently unable to provide informed consent, has no close relatives or guardian, the health care provider may according to section 18 (2) carry out a planned treatment, provided another qualified health care provider, who has not earlier participated in nor is going to participate in the treatment of said patient, consents to it. In order to protect the patient's rights it is important that the two involved health care providers are not dependent on each other. There must be no superior-subordinate relationship between the two.¹¹⁴

According to section 18 (3) the health care provider may when there is no closest relative or guardian even initiate treatment without the consent of another health care provider, if the treatment in question is only minor in terms of extent and duration. Examples are changing a bandage or taking the patient's temperature.¹¹⁵

If the health care provider finds that the closest relative or guardian, does not pay sufficient attention to the patient's best interest in connection with decision making, he may according to section 18 (4) proceed with the treatment if the health authorities (this is in practice a physician who is the local representative of the National Board of Health)¹¹⁶ approve this.

The rules mentioned in section 18 are only applicable when a patient is permanently unable to provide informed consent. For persons who temporarily lack the ability to make their own decisions the Health Act 2005 does not permit consent by proxy. This means that the closest relatives cannot consent to treatment on the incompetent patient's behalf. If the patient has a guardian and the guardianship covers personal matters, health matters included, the guardian can consent. This is a consequence of the fact that the statutory basis for the guardian's competence is the Act on Guardianship and not the Health Act 2005. Neither does the health care provider have the capacity – as is the case with regard to a permanently incompetent patient – to initiate treatment after having obtained the consent of an impartial colleague. The temporary lack of ability to consent can later result in a recovery of that ability or a permanent loss of it. In the first case the ordinary rules on

¹¹¹ U.HYBEL, 'Country Report Denmark', in J.TAUPITZ, Regulations of civil law to safeguard the autonomy of patients at the end of their life, Berlin, Springer, 2000, 498.


¹¹² U.HYBEL, 'Country Report Denmark', in J.TAUPITZ, Regulations of civil law to safeguard the autonomy of patients at the end of their life, Berlin, Springer, 2000, 498.

¹¹³ U.HYBEL, 'Country Report Denmark', in J.TAUPITZ, Regulations of civil law to safeguard the autonomy of patients at the end of their life, Berlin, Springer, 2000, 505.

¹¹⁴ U.HYBEL, 'Country Report Denmark', in J.TAUPITZ, Regulations of civil law to safeguard the autonomy of patients at the end of their life, Berlin, Springer, 2000, 499.

¹¹⁵ U.HYBEL, 'Country Report Denmark', in J.TAUPITZ, Regulations of civil law to safeguard the autonomy of patients at the end of their life, Berlin, Springer, 2000, 499.

¹¹⁶ U.HYBEL, 'Country Report Denmark', in J.TAUPITZ, Regulations of civil law to safeguard the autonomy of patients at the end of their life, Berlin, Springer, 2000, 499.



informed consent are to be followed; in the second case the rules laid down in section 18 as described above.¹¹⁷ Thus, Danish law does not regulate who may give informed consent in the period that someone is temporarily incompetent and has no guardian, which will often be the case. The only article that expressly refers to such a patient is section 19 of the Health Act 2005: if a patient who is temporarily (or permanently) unable to provide informed consent, is in a situation where immediate treatment is essential for the survival of the patient or long term improvement of the chances for survival or significantly improved results of treatment, a health care provider may initiate or proceed with treatment without consent from the patient, closest relative or guardian. According to section 20 of the Health Act 2005 a patient who is unable to provide informed consent must be informed and included in talks regarding the treatment, as far as the patient understands the treatment situation, unless this might damage the patient. Importance should be attached to the information provided by the patient, insofar as it is appropriate and relevant. According to the parliamentary preparatory documents, importance must also be attached to wishes that the patient has expressed prior to the treatment being needed – to the extent that these can still be considered current and relevant – and must be taken into consideration by the health care provider when deciding upon the treatment.¹¹⁸ Some people express their future wishes in powers of attorney documents. Such wishes are not legally binding but may serve as guidelines for the guardian who has been appointed.

e) Estonia¹¹⁹

The rights and obligations of patients are laid down in the Law of Obligations Act 2001 (hereafter: LOA 2001) which entered into force on 1 July 2002.

Legal conditions for a binding advance directive

Advance directives seem to be legally binding according to the LOA 2001. § 767 of this law which covers the provision of health care services to patients without capacity to exercise their will states: “(1) If a patient is unconscious or incapable of exercising his or her will for any other reason (a patient without the capacity to exercise his or her will) and if he 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 if this is in the interests of the patient and corresponds to the intentions expressed by him earlier or to his presumed intentions and if failure to provide health care services promptly would put the life of the patient at risk or significantly damage his or her health. The intentions expressed earlier by a patient or his or her presumed intentions shall, if possible, be ascertained using the help of his or her immediate family. The immediate family of the patient shall be informed of his or her state of health, the provision of health care services and the associated risks if this is possible in the circumstances.’

This article seems to imply the binding character of a previously expressed negative wish. The form of such an expression of will is not regulated. Neither exists a register of previously expressed wishes. An advance directive can be withdrawn by a person with or without capacity. An advance directive can be renewed simply by writing a new one.

¹¹⁷ Based on U.HYBEL, ‘Country Report Denmark’, in J.TAUPITZ, *Regulations of civil law to safeguard the autonomy of patients at the end of their life*, Berlin, Springer, 2000, 500.

¹¹⁸ U.HYBEL, ‘Country Report Denmark’, in J.TAUPITZ, *Regulations of civil law to safeguard the autonomy of patients at the end of their life*, Berlin, Springer, 2000, 500.

¹¹⁹ Based on H.NYS, et al., “Patient Rights in the EU – Estonia”, *European Ethical-Legal Papers*, N°5, Leuven, 2007.

Durable power of attorney in health matters

There is no regulation in Estonian law about proxy decision-making for incapacitated adults. The practice varies a lot: most of the times the treating physician takes the decision on behalf of the patient or in more rare cases a relative of the patient.

Representation by the relatives

Reference to the role of the relatives of the incapacitated patients is made in §767 (1) LOA 2001 in case of an emergency: 'the intentions expressed earlier by a patient or his presumed intentions shall, if possible, be ascertained using the help of his immediate family. The immediate family of the patient shall be informed of his state of health, the provision of health services and the associated risks if this is possible in the circumstances'. According to §767 (2) LOA 2001, immediate family means the spouse, parents, children, sisters and brothers of the patient. 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.

f) Finland

Finland was the first European to adopt a law on patient rights that came into force on 1 March 1993.¹²⁰ It has been amended afterwards for several times.

Legal conditions for a binding advance directive

Section 8 of the law on patient rights provides as follows:

'A patient has to be given treatment necessary to ward off a hazard imperilling his life or health even in the case it is not possible to assess the patient's will because of unconsciousness or another reason. However, if the patient has previously steadfastly and competently expressed his will concerning the treatment given to him, he must not be given a treatment that is against his will'. According to Kokkonen 'the patient's right to draft a valid living will is based on this provision, as is the right of a Jehova's witness to refuse a blood transfusion even after losing his consciousness'.¹²¹

- *Refusal of emergency treatment*

Only in case of emergency treatment, advance directives are legally binding. But in the legal literature it is stated that they are legally binding in other cases too. At least it is good medical practice to comply with them.¹²²

- *Formal aspects*

There is no set procedure for making advance directives. An advance directive can be made orally (e.g. by a person in a hospital) or in writing. If made in writing, it is advisable to have two witnesses. A physician and/or lawyer may be involved in the process of making an advance directive but this is not necessary. An advance directive can be amended, renewed or cancelled at any time. This can be done verbally, in writing or through behavior which clearly indicates this decision. It is not necessary for a person to have full legal capacity (i.e. in every domain) as a higher level of capacity is needed to write an advance directive than to cancel it.

- *Validity in time*

Advance directives are not limited to a set period of time.

¹²⁰ P.Kokkonen, 'The new Finnish law on the status and rights of a patient', *European Journal of Health Law*, 1994, 127-135; see for an English translation of this law www.finlex.fi.

¹²¹ P.Kokkonen, 'The new Finnish law on the status and rights of a patient', *European Journal of Health Law*, 1994, 131.

¹²² www.alzheimer-europe.org

- *Documentation and registration*

§ 18.4 of the decree of the Ministry of Social Affairs and Health on Medical Files (30.3.2009/298) states that if a patient wishes to express (orally) his steadfast will regarding future medical treatments, it should be recorded clearly, together with his signature, in the medical file. It is also possible to attach a separate advance directive to the medical file. Another method involves a written document that is kept at home, although in this case it is the responsibility of the patient and the patient's family and friends to ensure that the advance directive is delivered to the medical staff when necessary.

The non-binding directive

The Ministry of Social Affairs and Health has plans to alter the Act on Rights of Patients. After the alteration, doctors will not be obliged to comply with advance directives if it is obvious that the advance directive is based on a person's false perception of their health condition, the nature of the illness or the effectiveness of the treatment methods and medication proposed. Similarly, doctors should not comply with an advance directive if the patient's will concerning treatment and care has changed for the above-mentioned or a similar reason. If it would be against a doctor's personal beliefs to comply with instructions contained in an advance directive, the doctor must find a colleague who is willing to take over the treatment of the patient.

In this context it is interesting that nowadays positive advance directives are used in case of advanced dementia. These documents can express many items, e.g. how intensively you should investigate when new symptoms appear, what kind of food and drinks you like, what your favorite clothing is, what kind of music you like to hear, etc. If the personnel in an institution pays attention to these things, the quality of one's last years can be much better even for patients suffering from dementia.

Durable power of attorney in health matters

With regard to the appointment of a proxy decision-maker, no formal regulations exist in the Act on patient rights.¹²³ However a patient can appoint a 'continuing power of attorney in health care issues' in advance of his incapacity (Act on Continuing Powers of Attorney (648/2007)). Such donee is also a legal representative and also has the right to be informed under section 9.1 of the Act on the Status and Rights of Patients.

Representation by the relatives

Article 6 §2 and §3 of the Act on Rights of Patients stipulate the following.

§ 2: 'If a major patient because of mental disturbance or mental retardation or for other reason cannot decide on the treatment given to him, the legal representative or a family member or other close person of the patient has to be heard before making an important decision concerning treatment to assess what kind of treatment would be in accordance with the patient's will. If this matter cannot be assessed, the patient has to be given a treatment that can be considered to be in accordance with his/her personal interests.'

§ 3: 'In cases referred to in paragraph 2, the patient's legal representatives, a close relative, or other person closely connected with the patient, must give their consent to the treatment. In giving their consent, the patient's legal representatives, close relative, or other person closely connected with the patient must respect the patient's previously expressed wishes or, if no wishes had been expressed, the patient's well-being. If the patient's legal representatives, close relative, or other person closely connected with the patient forbid the care or treatment of the patient, care or

¹²³ P. Louhiala, 'Finland' in *Advance directives: towards a coordinated European perspective*, Zürich, Institute for Biomedical Ethics, June 2008, p.25.

treatment must, as far as possible in agreement with the person who refused consent, be given in some other medically acceptable manner. If the patient's legal representatives, close relative, or other person closely connected with the patient disagree on the care or treatment to be given, the patient shall be cared for or treated in accordance with his or her best interests' (amended by Law 489/1999).

Implementation of advance directives in practice¹²⁴

Less than 5% of hospital patients have an advance directive. There are no data on the general population.

g) France¹²⁵

In 2002 a far-reaching (in terms of French law at the moment) provision was introduced by Law n° 2002-303 of 4 April 2002 on the rights of patients in the Code of Public Health (section L1111-4). After being amended by Law n° 2005-370 of 22 April 2005 on the rights of patients and the end of life, section L1111-4 reads as follows:

'Each person takes his decisions regarding his health, in conjunction with the healthcare professional and taking account of the information and recommendations furnished by him'.

Legal conditions for the non-binding advance directives

The Law n° 2005-370 of 22 April 2005 on the rights of patients and the end of life has created the legal basis for advance directives by introducing section L 1111-11 in the Code of Public Health. It reads as follows:

'Every adult person may draft advance directives in case he is no longer capable to express his will. These advance directives indicate the wishes of the person concerning the conditions to limit or stop treatment at the end of life. They may be revoked at any time. On the condition that they have been made up three years before the person became unconscious the physician takes them into account before taking a decision to diagnose, intervene or treat'. But although the law attributes them a validity of only three years, it should be noted that the spirit of earlier wishes endures, particularly when no new advance directive has been written after three years.

The decree 2006-119 of 6 February prescribes the formal requirements for such an advance directives: written, dated and signed. There is no registration system for advance directives. According to the decree 2006-119 they have to be kept in the medical file of the patient.

Durable power of attorney in health matters

The possibility of designating a person of confidence, called in France a '*personne de confiance*', has existed since the law on the rights of patients of 2002. Article L.1111-6 of the Code of Public Health states:

'any adult may designate a person of confidence who can be a relative, a friend or a doctor, and who will be consulted should the person concerned be unable to express his wishes and to receive information necessary for this purpose. The designation is done in writing. It can be revoked at any time. If it is the wish of the patient the person of confidence accompanies him at every step and is present at medical appointments to help him reach decisions.'

To encourage people to appoint health care proxies, the law demands that in the event of hospitalization, the health care facility must suggest that the patient appoints a person of confidence

¹²⁴ P. Louhiala, 'Finland' in *Advance directives: towards a coordinated European perspective*, Zürich, Institute for Biomedical Ethics, June 2008, p.26.

¹²⁵ Partially based on H.Nys, 'Physician involvement in a patient's death: a continental European perspective' in T.S. Jost (ed), *Readings in comparative health law & bioethics*, Durham, Carolina Academic Press, second edition, 2007, 285-289. For a very critical discussion of advance directives in France see B. Feuillet, 'Les directives anticipées en France, un indice de consentement à effets limités' in S.NEGRI, *Self-Determination, Dignity and End-of-Life Care. Regulating Advance Directives in International and Comparative Perspective*, Leiden-Boston, Martinus Nijhoff, 2011, 195-207.

for the duration of the hospital stay. The patient is free to refuse or agree to choose a health care proxy. The person of confidence does not have the power to decide in the place of the patient.

By creating a “*mandat de protection future*”, the law of 5 March 2007 reforming the legal protection of adults introduced a durable power of attorney in health care. This mandate allows any competent person to designate, in view of a time when he will no longer be able to manage his own life alone, one or several other persons to act as his representative(s) in all personal matters, including health care.

Representation by the relatives

The close relatives of an incompetent patient have no legal right to represent an incompetent patient. In the past the jurisprudence recognized their role as ‘natural protectors’ and required their consent for a medical intervention but this obligation seems to be replaced by an obligation to inform or consult them in certain hypotheses.¹²⁶

h) Germany

The act of 29 July 2009 amending the guardianship legislation has given a legal status to advance directives regarding health matters in Germany. It entered into force on 1 September 2009.¹²⁷ Article 1 of the act has incorporated rules concerning a patient’s advance directive in the chapter on guardianship-law of the German Civil Code (GCC).¹²⁸ The newly incorporated articles 1901a and 1901b of the GCC are governing the patient’s advance directives.

Legal conditions for a binding advance directive

- Refusal of well determined and medically indicated interventions

According to article 1901a, section 1 GCC, an advance directive has to relate to a well determined medical intervention and this has important practical consequences. General formulations or guidelines for a future, not well described medical treatment cannot be considered as an advance directive. However, like verbal expressions of the will, these general statements may have a certain significance. Even when an advance directive relates to a well determined medical intervention, it nevertheless may require often some kind of interpretation. In that case one should not stick to the literal formulation but check what the patient would have really wanted.¹²⁹ With regard to their binding force, there is an important difference between positive and negative advance directives because neither the patient nor his health care attorney¹³⁰ can enforce a medically non indicated

¹²⁶ B. Feuillet, ‘Les directives anticipées en France, un indice de consentement à effets limités’ in S.NEGRI, *Self-Determination, Dignity and End-of-Life Care. Regulating Advance Directives in International and Comparative Perspective*, Leiden-Boston, Martinus Nijhoff, 2011,199.

¹²⁷ Based on H.NYS, ‘The growing significance of advance declarations of will as an expression of the autonomy of the patient in Europe’ in A.VERBEKE (Eds.), *Confronting the frontiers of family and succession law. Liber amicorum Walter Pintens*. Cambridge, Intersentia, 2012,1047-1064 and J.TAUPITZ and A. SALKIC, ‘Advance directives and legality of euthanasia under German law’, in S.NEGRI,*Self-Determination, Dignity and End-of-Life Care. Regulating Advance Directives in International and Comparative Perspective*, Leiden-Boston, Martinus Nijhoff, 2011, 346.

¹²⁸ See on this law, inter alia, M.ALBERS, Zur Rechtlichen Ausgestaltung von Patientenverfügungen, *Medizinrecht* 2010, 138-144; R. BECKMAN, Patientenverfügung: Entscheidungswege nach der gesetzlichen Regelung, *MedizinRecht*,2009,582-586; T.DHIEN and R.REBHAN, Vorsorgevollmacht und Patientenverfügung, *Neue Juristische Wochenschrift*,2010, 326-331; W.HÖFLING, Das neue Patientenverfügungsgesetz, *Neue Juristische Wochenschrift*,2009, 2849-2852; K.KUTZER, Arztliche Pflicht zur Lebenserhaltung unter besonderer Berücksichtigung des neuen Patientenverfügungsgesetz,*MedizinRecht*,2010,531-533; U. WIESING,et al, A new law on advance directives in Germany, *Journal Medical Ethics*, 2010, 779-783.

¹²⁹ K. KUTZER, Arztliche Pflicht zur Lebenserhaltung unter besonderer Berücksichtigung des neuen Patientenverfügungsgesetz,*MedizinRecht*,2010,532.

¹³⁰ Attorney is the person granted power of attorney by the patient.

intervention from the treating physician.¹³¹ In this sense a positive advance directive has no binding force.

Article 1901a, section 3 GCC provides that an advance directive is valid whatever the nature and the stage of the disease the patient is suffering from. This means in other words that the validity of an advance directive does not require a terminal illness that will irreversibly cause the death of the patient.¹³² Any restriction would violate the right to physical integrity guaranteed by the German constitution because it forces incompetent patients to undergo medical treatments against their will.¹³³ Hence, a negative advance directive may be valid also when a patient is in a vegetative state without being terminally ill. And its validity is not limited to medical treatment at the end of the life of the patient.¹³⁴

Article 1901a, section 4 GCC stipulates that no one can be compelled to make up an advance directive. The same disposition contains a so called 'coupling ban' which means for instance that the admission to a nursing home may not be made dependent upon the writing of an advance directive.

- *Formal aspects*

Article 1901a, section 1 provides that an adult person (18 years or older) who is capable of giving consent may determine in writing that he gives or refuses his consent for well determined diagnostic procedures or medical treatments in the future. The act does not contain additional formal requirements. A notarial act is not required as this is experienced as excessive.¹³⁵ Such an advance directive may always be revoked, without formal requirements.

- *Information and professional advice*

The act does not contain an obligation to ask for an advice of a physician when making up an advance directive. This lack of counseling has been criticized by several authors. According to Albers, counseling could compensate the absence of a dialogue between the physician and the author of the advance directive once he has become incompetent.¹³⁶ An advance directive is ultimately a form of instruction by a patient to his future physician and therefore Wiesing et al. wonder whether it is not completely sensible to seek medical counseling before writing an advance directive.¹³⁷ To others, this lack of counseling creates no problem because when a patient makes up an advance directive without being aware of its consequences, he may be considered to waive his right to information.¹³⁸

¹³¹ K. KUTZER, Arztliche Pflicht zur Lebenserhaltung unter besonderer Berücksichtigung des neuen Patientenverfügungsgesetz, *MedizinRecht*, 2010, 531.

¹³² M. ALBERS, Zur Rechtlichen Ausgestaltung von Patientenverfügungen, *Medizinrecht* 2010, 141.

¹³³ M. ALBERS, Zur Rechtlichen Ausgestaltung von Patientenverfügungen, *Medizinrecht* 2010, 141.

¹³⁴ W. HÖFLING, Das neue Patientenverfügungsgesetz, *Neue Juristische Wochenschrift*, 2009, 2850. See also U. WIESING, et al, A new law on advance directives in Germany, *Journal Medical Ethics*, 2010, 781.

¹³⁵ M. ALBERS, 'Zur Rechtlichen Ausgestaltung von Patientenverfügungen', *Medizinrecht* 2010, 142.

¹³⁶ M. ALBERS, Zur Rechtlichen Ausgestaltung von Patientenverfügungen, *Medizinrecht* 2010, 142.

¹³⁷ U. WIESING, et al, A new law on advance directives in Germany, *Journal Medical Ethics*, 2010, 781.

¹³⁸ R. BECKMAN, Patientenverfügung: Entscheidungswege nach der gesetzlichen Regelung, *MedizinRecht*, 2009, 585.

- *Validity in time*

An advance directive does not have to be renewed periodically which means that it has no expiry date.¹³⁹

- *Documentation and registration*

The act has not provided a formal system for the registration of advance directives. A physician is not under a legal obligation to check whether an incompetent patient has made up an advance directive.¹⁴⁰

The non-binding advance directive

General formulations or guidelines for a future, not well described medical treatment cannot be considered as an advance directive. However, like verbal expressions of the will, these general statements may have a certain significance.

Durable power of attorney in health matters

The Act on advance directives has placed the legal representative of an incompetent patient appointed by the Guardianship court on equal footing with the attorney. However, the legislator clearly favours attorneys mandated by a patient as article 1896 section 1 GCC stipulates that no legal representative can be appointed for an incompetent person when his interests can be taken care of by an attorney.

There are no specific rules that govern health care attorneys for incompetent patients. The general rules of the GCC on representation and mandate (Book 1, Chapter 3, Title 5) also apply to the attorney mentioned in article 1901a, b and c GCC. This mandate may also contain an advance directive. Article 1901a, section 2 GCC contains some rules that prescribe how an attorney has to fulfil his tasks. When an incompetent patient has not made an advance directive or his advance directive does not match his actual living and health situation, the attorney has to ascertain the treatment wishes or the so called presumed will of this patient. The attorney should then decide whether or not he consents to the intervention proposed by the treating physician. The presumed will of the incompetent patient may be deduced from concrete indications. In particular the attorney has to pay attention to previous verbal or written declarations of the patient that have not the status of an advance directive, his ethical or religious convictions and other personal value opinions (article 1901a, section 2 GCC). The notion of presumed consent remains subjected to criticism. For instance, Beckman has fundamental objections to this notion because it is not very convincing to speak of the presumed will of someone who cannot form a will anymore due to his incompetence. Based on the criteria mentioned in article 1901b, section 2 one can only determine with a certain degree of probability someone's will. He therefore prefers the term 'probable will' instead of 'presumed will', which is nothing more than a fiction to justify decisions.¹⁴¹ This criticism has not prevented the legislature from attributing binding force to the presumed will of an incompetent patient. When there is a consensus between the attorney and the treating physician regarding the presumed will of the patient, it has to be respected and no intervention of the guardianship court is required. The Act does not regulate the case of an incompetent patient who has not made an advance directive while it is also impossible to construe his presumed will, although this is not an exceptional situation.¹⁴² The Criminal Senate of the Federal Supreme Court has judged that in such a case one has to act according

¹³⁹ J. TAUPITZ and A. SALKIC, 'Advance directives and legality of euthanasia under German law', in S. NEGRI, *Self-Determination, Dignity and End-of-Life Care. Regulating Advance Directives in International and Comparative Perspective*, Leiden-Boston, Martinus Nijhoff, 2011, 346.

¹⁴⁰ T. DHIEN and R. REBHAN, *Vorsorgevollmacht und Patientenverfügung*, *Neue Juristische Wochenschrift*, 2010, 328.

¹⁴¹ R. BECKMAN, 'Patientenverfügung: Entscheidungswege nach der gesetzlichen Regelung', *MedizinRecht*, 2009, 584-585.

¹⁴² R. BECKMAN, 'Patientenverfügung: Entscheidungswege nach der gesetzlichen Regelung', *MedizinRecht*, 2009, 585.

to the general opinions regarding a human dignified life, while the Civil Senate of this Court judged that the welfare of the patient should be the decisive criterion because this matches better with the law on representation in general (article 1901 GCC). Acting in the welfare of a patient means that in cases of doubt one has to give priority to the life of the patient (*in dubio pro vita*).¹⁴³

Article 1904 GCC requires the approval of certain medical interventions practiced upon an incompetent patient by the guardianship court. This article existed before the Act on advance directives which has amended its contents. According to this article the approval of the court is required for a medical intervention if there is a serious risk that following this intervention the patient will die or may suffer severe and lasting damage to his health. The approval may not be refused if the consent to the intervention given by the attorney matches the (presumed¹⁴⁴ or real) will of the patient. No approval has to be solicited when there is a consensus between the attorney and the treating physician that the intervention matches with the will of the patient (article 1904 section 4 BGB).

Representation by the relatives

German legislation does not leave room for informal representation by relatives of the incompetent patient.¹⁴⁵

Implementation of advance directives in practice

According to T. Dhien and R. Rebhan¹⁴⁶ more than 700.000 advance directives have been registered on a voluntary basis in the central advance directive register of the Federal Chamber of notaries; according to a source cited by R. Beckman,¹⁴⁷ 82,2% of persons interviewed (in 2009) declared not to dispose of an advance directive. In Germany, it was estimated that more than 1.5 million continuing powers of attorney had been set up by autumn 2008, and the proportion of adults whose affairs were not managed by a publicly appointed legal representative, but instead by an attorney, was constantly increasing. According to a recent study, the proportion of the total number of residents in German care homes for the elderly who were represented by an attorney amounted to 30%.¹⁴⁸

i) Hungary¹⁴⁹

The primary legal sources of patient rights is the Parliamentary Act No. CLIV of 1997 on health care (hereafter: Health Care Act). The protection of the patient rights is one of the most important reforms accomplished by the Health Care Act.

Legal conditions for a binding advance directive

Although the Hungarian law does not use the term 'advance directive' the concept to refuse life sustaining medical treatment in advance exists. The Health Care Act contains detailed provisions concerning previously expressed negative wishes. According to section 22 a person with full disposing capacity may draw up an advance directive that might be relevant if later on he becomes incompetent.

¹⁴³ K.KUTZER, 'Arztliche Pflicht zur Lebenserhaltung unter besonderer Berücksichtigung des neuen Patientenverfügungsgesetz', *MedizinRecht*, 2010, 532

¹⁴⁴ R. BECKMAN, 'Patientenverfügung: Entscheidungswege nach der gesetzlichen Regelung', *MedizinRecht*, 2009, 586

¹⁴⁵ S.Gevers, J.Dute and H. Nys, 'Surrogate decision-making for incompetent elderly patients: the role of informal representatives', *European Journal of Health Law*, 2012, 64.

¹⁴⁶ T. DHIEEN and R. REBHAN, 'Vorsorgevollmacht und Patientenverfügung', *Neue Juristische Wochenschrift*, 2010, 326.

¹⁴⁷ R. BECKMAN, 'Patientenverfügung: Entscheidungswege nach der gesetzlichen Regelung', *MedizinRecht*, 2009, 586.

¹⁴⁸ Explanatory Memorandum to Rec (2009)11 § 30

¹⁴⁹ S.DEFLOOR, et al., "Patient Rights in the EU – Hungary", *European Ethical-Legal Papers*, N°11, Leuven, 2007.

- *Life-supporting and life-saving interventions in case of an incurable illness*

Life-supporting or life-saving interventions may be refused when the incompetent patient suffers from a serious incurable illness which -according to the current state of medical science- will lead to death within a short period of time even with adequate health care, or if he suffers from an incurable disease and as a consequence of that disease he is unable to care for himself physically or his pain cannot be eased with appropriate therapy (section 22 §1).

A rather unique provision is that a competent person may in an advance directive appoint a competent person who shall be entitled to exercise the right to draw up an advance directive in his place (section 22 §2).

- *Formal aspects*

The advance directive has to take the form of a notarial act. According to section 22 §3 the statement is only valid if a qualified psychiatrist has confirmed in a written opinion that the person made the decision in full awareness of its consequences. The medical opinion of the psychiatrist cannot be older than one month. An advance directive may be withdrawn at any time, regardless of the patient's disposing capacity and without formal requirements.

- *Validity in time*

The advance directive has to be renewed every two years.

- *Documentation and registration*

There is no register of advance directives.

Durable power of attorney in health matters

According to section 16 §1 of the Health Care Act a person with full disposing capacity may appoint a competent person who shall be entitled to exercise the right to consent and refuse in his place. This statement has to be incorporated into a notarial document, into a fully conclusive private document or -in the case of inability to write- a declaration made in the joint presence of two witnesses. When the attorney refuses a treatment, a committee composed of three physicians defined in section 20 § 4 shall make a decision on whether the conditions set out in section 22 §1 exist (see above) and whether the person who is entitled to make those decisions instead of the patient, has made the decision in full awareness of the consequences.

Representation by the relatives

If a patient is incompetent and he has not indicated any person who would be entitled to exercise the right to consent and refusal, section 16 § 2 of the Health Care Act lists the persons who are entitled to exercise in the specified order these rights within the limits stipulated by section 16 §4. The specified order is the following:

- a) *the patient's legal representative, in absence thereof;*
- b) *the following individuals with full disposing capacity and sharing household with the patient:*
 - a. the patient's spouse, in the absence thereof,
 - b. the patient's child, in the absence thereof,
 - c. the patient's parent, in the absence thereof,
 - d. the patient's sibling, in the absence thereof,
 - e. the patient's grandparent, in the absence thereof,
 - f. the patient's grandchild;
- c) *in the absence of a relative indicated in paragraph b), the following individuals with full disposing capacity and not sharing household with the patient:*
 - a. the patient's child, in the absence thereof,
 - b. the patient's parent, in the absence thereof,
 - c. the patient's sibling, in the absence thereof,
 - d. the patient's grandparent, in the absence thereof,
 - e. the patient's grandchild.

According to section 16 §3 in the case of contrary statements made by the individuals qualified in the same line to make a statement, the decision that is likely to impact upon the patient's state of health shall be taken into account most favorably. The persons defined in section 16 § 2 are entitled to exercise the right of consent and refusal within the limits set out in section 16 §4. According to this section their decision has to be made after information in accordance to section 13 has been provided. With the exception of the refusal of life-supporting or life-saving interventions the decision statement may not unfavorably affect the patient's state of health and in particular may not lead to serious or lasting impairment to the health. This means that taking into account the patient's health status may prevail over the right of consent of his representative.

j) Latvia

The law on the rights of patients was enacted on 17 December 2009 and entered into force on 1 March 2010.¹⁵⁰ Section 7 deals with consent or refusal of a medical treatment by another person than the patient himself.

Legal conditions for advance directives

The law on the rights of patients only briefly deals with advance directives in section 7 §2 which states:

' The spouse or closest relative of a patient or a person authorised by the patient, as well as the lawful representative of the patient if the patient is under guardianship or trusteeship, when taking a

¹⁵⁰ See for an English translation of the act www.vvc.gov.lv

decision regarding medical treatment or refusal thereof, *shall observe the wish previously expressed by the patient in relation to medical treatment*'. No other details are given.

Representation by the relatives

If a patient is unable to take a decision regarding medical treatment due to his or her state of health or age, the spouse of the patient has the right to take a decision regarding the medical treatment. If there is no spouse, an adult relative with capability to act may decide in the following order: the children of the patient, the parents of the patient, the brother or sister of the patient, the grandparents of the patient or the grandchildren of the patient (section 6 §1).

k) Luxembourg

The Law of 16 March 2009 relating to palliative care, advance directives and accompaniment at the end of life contains a section on advance directives.

Legal conditions for a non-binding advance directive

- *Scope: End-of-life treatment*

A person can express in the advance directive his wishes concerning end-of-life treatment and care. This might include the conditions, limits and withdrawal of treatment, including the treatment of pain, as well as psychological and spiritual accompaniment that he would like to receive should he be in an advanced or end stage of a serious and incurable condition and unable to express his wishes.

Article 4 of this law states that doctors must try to establish the patient's presumed will which involve checking whether he wrote an advance directive. The doctor must take into consideration the advance directive in a patient's medical file or which has come to his attention. He/she must evaluate whether the provisions contained in the document correspond to the situation envisaged by the terminally ill patient and take into consideration developments in medical science since it was written. If the doctor decides not to follow the patient's previously expressed wishes as contained in the document, he must record the reasons for this in the patient's medical file and inform the person of confidence, or if there is none, the patient's family.

- *Formal aspects*

The advance directive and any amendments must be dated and signed by the patient. The advance directive can be revoked at any time.

- *Documentation and registration*

The advance directive should be available to any doctor responsible for the care of the patient in the terminally ill stage. Alternatively, the patient is free to give the advance directive to medical staff on the occasion of a hospitalization or at any moment to his regular doctor. In all cases, the document should be included in the patient's medical or care file.

Durable power of attorney in health matters

In an advance directive a 'person of confidence' can be appointed. Doctors should consult him about end-of-life issues when the patient is no longer able to express his will. However he does not represent the incompetent patient. Article 14 of a bill on the rights and obligations of patients that has been deposited in the Chamber of Representatives on 21 August 2012 provides for the possibility to appoint a health care attorney.¹⁵¹

¹⁵¹ Projet de loi N° 6469, session ordinaire 2011-2012.

I) Netherlands¹⁵²

Negative advance directives received statutory recognition in 1995, in the framework of the so called Law on Medical Treatment Contracts. This law has amended the Dutch Civil Code (DCC) in order to protect the rights of the patients.

Legal conditions for a binding advance directive

- *Scope: any medical intervention*

Article 450§3 of the DCC states the following:

'In case a patient of 16 years of age or older cannot be considered capable of a reasonable assessment of his relevant interests, the healthcare provider shall follow the patient's apparent views laid down in writing when he was still capable of such reasonable assessment and containing a refusal of consent (...) The healthcare provider may depart here from if he considers that there are well-founded reasons for doing so'.

The possibility to deviate from an advance directive has been criticized for its vagueness. It is generally accepted that the doctor's personal views, medical professional standards and the possible life-shortening effect of foregoing treatment, are not 'well-founded reasons' for giving treatment against the patient's express wishes. The phrase 'well-founded reasons' refers to situations of uncertainty with regard to the identity of the patient; the patient's competence at the time of the drafting; the actual correspondence between the content of the directive and the wishes of the person at the time of drafting and the actual correspondence between the conditions of applicability in the directive and the current situation of the (formerly competent) author.

- *Formal aspects*

The advance directive must be a written document. The identity of the person drafting the advance directive must be certain. Furthermore there should be no doubt about the authenticity of the document. Patients may retract or modify an advance directive at any time.

- *Validity in time*

There is no limitation in time. Although the law does not set a time requirement for the validity of an advance directive, a recently drafted or renewed document can minimize the uncertainty concerning the consistency between the instructions in the directive and the current wishes of their author. In a fact sheet produced by the Ministry of Health, Welfare and Sport (1995), it is stated that in any case, advance directives must be clear and have been made fairly recently.

- *Documentation and registration*

No national register of advance directives exists in the Netherlands. In a fact sheet produced by the Ministry of Health, Welfare and Sport (1995), it is stated that care providers are not obliged to search for such statements in emergency situations.

¹⁵² Based on S. Moratti and C. Vezzoni, 'Treatment directives in the Netherlands' in S.NEGRI, *Self-Determination, Dignity and End-of-Life Care. Regulating Advance Directives in International and Comparative Perspective*, Leiden-Boston, Martinus Nijhoff, 2011, 287-298.

Durable power of attorney in health matters

According to article 465 §3 DCC it is possible to appoint an attorney in health care:

'If an adult patient cannot be considered capable of a reasonable assessment of his relevant interests and he has not been placed under guardianship or had a mentor appointed for his benefit, then the obligation on the part of the healthcare provider towards the patient arising from the Law on contracts for medical treatment, shall be fulfilled towards the person authorized in writing by the patient to act on his behalf'.

Except where a guardian or a mentor has been appointed by a court, the attorney appointed by the patient in a written directive takes precedence over the patient's relatives. If the behavior of the attorney is 'not compatible with the level of care expected from a conscientious provider', doctors and nurses can refuse to comply with the representative's instructions.

Representation by the relatives

If no attorney was appointed, the physician has the duty to consider the partner as a proxy decision-maker. If there is no partner, or he is unable or unwilling, a parent, a child, a brother or sister becomes the proxy decision-maker.

Implementation of advance directives in practice

The implementation of advance directives in the Netherlands is not unproblematic, especially in the case of patients who suffer from a condition that causes impairments that worsen over time such as Alzheimer's disease. In an advance directive drafted while still competent, the patient may choose to set a specific boundary that he should never like to cross (eg not being able to recognize one's own children). After that boundary has been crossed, the alert but incompetent patient may appear altogether serene and smiling, notwithstanding his condition and severe cognitive impairment. In that situation, the caregivers may be unsure whether (and when) to carry out a decision to forego a given life-saving treatment by the patient in his advance directive.¹⁵³

m) Portugal¹⁵⁴

The law n° 25/2012 of 16 July 2012¹⁵⁵ contains rules on advance directives.

Legal conditions for a binding advance directive

- Scope

An adult and competent person may declare in advance his will, in a conscious and free manner, concerning the healthcare treatment he wants or not to receive in case he becomes incompetent to consent, more specifically not being submitted to artificial support of vital functions; not being submitted to futile or useless or disproportionate treatment according to good clinical practice, namely in what concerns the basic measures of life support and hydration and nutrition measures that only aim to delay the natural process of death.

¹⁵³ S. Moratti and C. Vezzoni, 'Treatment directives in the Netherlands' in S.NEGRI, *Self-Determination, Dignity and End-of-Life Care. Regulating Advance Directives in International and Comparative Perspective*, Leiden-Boston, Martinus Nijhoff, 2011, 296-297.

¹⁵⁴ Based on a presentation of A.Pereira (University of Coimbra) at the World Congress of Medical Law, Brazil, 9 August 2012.

¹⁵⁵ Lei n.º 25/2012 de 16 de julho Regula as diretivas antecipadas de vontade, designadamente sob a forma de testamento vital, e a nomeação de procurador de cuidados de saúde e cria o Registo Nacional do Testamento Vital (RENTEV).

The medical team shall respect the content of the advance directive. The advance directive may not be followed if it can be demonstrated that the patient would not want the advance directive to be respected or if the advance directive is clearly outdated given the progress of medical technology. The decision not to respect the advance directive has to be documented in the patient file.

- *Formal aspects*

An advance directive has to be signed in front of a notary or be deposited in the National Registry of Advance Directives. It can be always revoked.

- *Validity in time*

An advance directive is valid until 5 years after it is being signed. If the patient becomes incompetent during the 5 year time limit, it is not valid anymore.

- *Documentation and registration*

The law on advance directives has established a National Registry of Advance Directives. The Ministry of Health approves, after advice of the National Council of Ethics and the National Data Protection Commission, a model of advance directive that may be used by the patient.

Durable power of attorney in health matters

In an advance directive one can nominate another person, relative or not, to take decisions in case of incompetency.

n) Slovenia¹⁵⁶

The Patient Rights Act of 2008 deals with previously expressed wishes (Articles 32-34).

Legal conditions for binding advance directives

- *Scope : terminally illness*

Article 34 of the Patient Rights Act provides that every patient with full disposing capacity may refuse in an advance directive treatment when he is in a position where he is incapable of expressing his will in case:

a) *he is terminal ill or*

b) *suffers from a disease for which treatment would not lead to an improvement in health or the alleviation of his suffering but rather only to the prolonging of his life or he would end up being in a state where, due to the graveness of his disability, he would lose physical and mental ability to take care of himself.*


The patient's previously expressed wishes regarding treatment related to the first case (a) is binding for the attending doctor, whereas in the second case (b) the patient's wishes are considered by the doctor as a guide in deciding on the course of procedure.

The patient's previously expressed wishes must be considered in all such situations, save in cases where there is reasonable grounds to suspect that the patient would have revoked his wishes.

- *Formal aspects*

The patient's previously expressed wishes must be drafted on a special form (Article 27). The patient's personal physician or his representative should remind him of the consequences of his decisions in expressing wishes regarding future treatment. The special form containing a patient's previously expressed wishes regarding treatment must contain information on whether the person

¹⁵⁶ Partially based on V. Žnidaršič Skubic, 'Slovenia' in "Patient Rights in the EU Slovenia", *European Ethical-Legal Papers* N°16, Leuven, 2008.



fulfills the conditions for informed consent (full disposing capacity, legal age) and basic explanations regarding the decision, as well as the patient's signature, name of his personal doctor and authorized health representative (Article 27).

An advance directive can be withdrawn by the patient at any time. The withdrawal must be in writing. It is not clear whether the patient has to have full disposing capacity to do this.

- Validity in time

The written statement regarding a wish for future treatment is valid for five years from the date of signature and can be withdrawn by the patient in writing at any time.

- Documentation and registration

Details of the patient's wishes are added to his/her medical card or main medical file.

An attending doctor obtains information on a patient's previously expressed wishes regarding treatment on his medical card or in main health records.

Durable power of attorney in health matters

A patient who is of legal age and has full disposing capacity may assign a competent person who shall be entitled to exercise the right to consent and refusal in his name in the event that he is unable to decide on medical treatment or other rights stemming from this Act. The patient's authorised representative in this case must be of legal age and have full disposing capacity. The representative has the right to be acquainted with the patient's health record and his/her state of health as well as to obtain all information that may be relevant in deciding on whether to consent to treatment.

A patient can name an authorised representative with a written authorisation. The signature on the authorisation must be notary verified. In the written authorisation, the patient can set down instructions or guidelines for his representative or set down limitations to the access to the medical files or information on his medical condition. The patient can withdraw in writing his authorisation at any time. Similarly, an authorised representative can withdraw in writing from his role, save in cases where this could result in serious harm to the health of the patient. The name, birth information and contact details of a patient's authorised representative is contained on his health card or in their main medical files.

Along with the right to an authorised representative, a patient also has the right to decide to exclude persons who would otherwise be entitled to take decisions on treatment on his behalf. Patients can exclude or limit the powers of such persons in writing, given that they have full disposing capacity and are of legal age. Information on such wishes is contained on the health card or main medical files of the patient.

Representation by the relatives

Until a legal representative is named, the following persons are entitled to exercise, in the specified order, the right to consent or refusal, provided that they are of legal age and have full disposing capacity: a) The patient's spouse, or partner in cases of civil unions; b) The patient's children or adopted children; c) The patient's parents or foster parents; d) The patient's brothers or sisters; e) The patient's grandparents; f) The patient's grandchildren. If one or more of the above listed persons refuse consent, the doctor shall decide on the course of action on the basis of all of the opinions given and the patient's best interests. The patient's legal representative and other persons listed above to decide on behalf of an incapacitated adult patient cannot refuse emergency (life-saving) medical treatment.

o) Spain¹⁵⁷

In November 2002 the Spanish Parliament passed Basic Law 41/2002 on the autonomy of the patient and the rights and obligations with regard to clinical information and documentation (the Patient Rights Law, hereafter PRL).¹⁵⁸ Besides this state regulation, applicable on the entire Spanish territory, all Autonomous Communities¹⁵⁹ possess their own regulation of advance directives, resulting in a huge normative body which contains diverse institutions of advance care planning.¹⁶⁰

Legal conditions for binding advance directives

Article 11 §1 of the PRL states the following:

‘By means of the document of prior instructions, an adult person who is competent and free states in advance his will regarding healthcare and treatments or after his death, the destination of his body or his organs, with the aim that his will be complied when he is no longer competent to express them personally.’

- *Contents: medical interventions in general*

In an advance directive a patient can decide both on the intervention he does not wish to receive and on the interventions and care which he wishes to receive in concrete clinical situations, including the withholding and the withdrawal of life-sustaining treatments as well as decisions on palliative treatment, sedation, comfort and other measures. Article 11 §2 leaves it to the Autonomous Communities to regulate the appropriate procedure so that compliance with the advance directives is guaranteed. Advance directives that are contrary to the legal order, the *lex artis* (good medical practice) or do not correspond with the actual situation in which they have to be implemented will not be applied. The clinical record of the patient has to contain the reasons explaining the lack of correspondence (article 11 §3).

- *Formal aspects*

Advance directives have to be drafted in writing (article 11 §2). The Autonomous Communities have regulated in great detail the formal and procedural requirements, establishing two general procedures to issue advance directives (before a notary or before 3 witnesses). Advance directives may be freely revoked at any moment, recording it with a written statement (article 11 §4).

- *Validity in time*

There is no limitation in time so that renewal of advance directives is not necessary in order to remain valid. However, a lack of renewal could impact upon the efficacy of advance directives in some cases (eg a considerable length of time has passed and a notable change in conditions or values stated in the advance directive, contravening the patient’s initial purpose).

- *Documentation and registration*

In order to ensure in the entire national territory the efficacy of advance directives expressed by patients and formalised in accordance with the provisions contained in the legislation of the

¹⁵⁷ Based on J.A. Seoane, ‘Advance directives in Spain’ in S.NEGRI, *Self-Determination, Dignity and End-of-Life Care. Regulating Advance Directives in International and Comparative Perspective*, Leiden-Boston, Martinus Nijhoff, 2011,299-317 and P.Simon-Lorda a.o. , ‘Advance directives in Spain. Perspectives from a medical bioethicist approach’, *Bioethics*,2008,p.346-354.

¹⁵⁸ M.T. Requejo, ‘Legal analysis of the Spanish Basic Law 41/2002 on the autonomy of the patient and the rights and obligations with regard to clinical information and documentation’, *European Journal of Health Law*, 2003,257-269.

¹⁵⁹ The Spanish State consists of 17 Autonomous Communities and 2 Autonomous Cities. Each Autonomous Community has authority to legislate in health matters, including advance directives (article 149 Spanish Constitution).

¹⁶⁰ See for more details J.A. Seoane, ‘Advance directives in Spain’ in S.NEGRI, *Self-Determination, Dignity and End-of-Life Care. Regulating Advance Directives in International and Comparative Perspective*, Leiden-Boston, Martinus Nijhoff, 2011,299-317 and especially the Appendix: Legal norms on advance directives in Spain at p.318-329 (in Spanish).

respective Autonomous Communities a national register of prior instructions has been created within the Ministry of Health and Consumer Affairs, governed by the rules determined in regulations, with prior agreement from the Inter-territorial Council of the National Health System (article 11 §5). There exist also Autonomous Communities' Registries. Their main objectives are to collect information on advance directives (the existence of the document, the place and date of inscription, the contents) and facilitate healthcare professionals in knowing about the advance directive and its consultation in the event that it must be applied. Registration is voluntary and has merely a declarative effect so that the validity of the advance directive does not depend on its registration¹⁶¹

Durable power of attorney in health matters

In an advance directive the author can designate a representative who acts as an interlocutor with the doctor or medical team to ensure that advance directives are complied with (article 11 §5 PRL). The function of the representative is helping the healthcare providers to interpret patient's wishes and guaranteeing respect of values and the compliance of instructions included in the advance directive. Issuing an advance directive is so personal that it can only be exercised by the patient himself. This is not a right that can be exercised by proxy.

Representation by the relatives

When a patient is not capable of taking decisions in the opinion of the doctor responsible for the care, or his or her physical or mental state does not permit him to appreciate the situation and if the patient lacks any legal representation, consent has to be granted by persons having ties to the patient by virtue of family or *de facto* reasons (article 9 §3 a PRL).

Implementation of advance directives in practice

At 1st January 2008: 43,668 individuals (61% women; 39 % men) have filled in and registered advance directives in regional registry offices (96/100,000 inhabitants; approx. 0,1%. 120/100,000 over 18 inhabitants; 0,12%) (Observatorio de voluntades anticipadas. Escuela Andaluza de Salud Pública, *Informe semestral sobre voluntades anticipadas en España (1 de enero de 2008)* [Observatory on advance directives.Andalusian School of Public Health, *Semestral Report on advance directives in Spain (1st January 2008)*].¹⁶²

p) United Kingdom (England and Wales)¹⁶³

English law protects patient autonomy in decision-making. A competent adult patient has an absolute right to refuse to consent to medical treatment even where that refusal may lead to the patient's death. In England and Wales, advance refusals of treatment are legally valid under the Mental Capacity Act 2005 (MCA), sections 24-26.

¹⁶¹ In some Autonomous Communities (eg Andalusia,Cantabria) the registration of advance directives is mandatory.

¹⁶² Information provided by Pablo Simón, EASP.

¹⁶³ Based on P.Lewis, 'The limits of autonomy: law at the end of life in England and Wales' in S.NEGRI, *Self-Determination, Dignity and End-of-Life Care. Regulating Advance Directives in International and Comparative Perspective*, Leiden-Boston, Martinus Nijhoff, 2011, 221-247 and A.R.Maclean, 'Advance directives and the rocky waters of anticipatory decision-making', *Medical Law Review*,2008,1-22. In Scotland the 'Adults with Incapacity (Scotland) Act' applies. According to Mason and Laurie 'both Acts follow the same pattern but there are a number of relatively subtle differences', J.K.Masson and G.T. Laurie, *Law and medical ethics*, Oxford, Oxford University Press, Seventh Edition, 2006, 453-454. In Scotland, the present regime of continuing powers of attorney was introduced in 2001. Since then, the registrations have continued to grow. Documents are most commonly registered at the time of granting, rather than later at the time of loss of capacity. 5,592 powers of attorney were registered in the year to 31 March 2002. The number rose to 18,113 in the year to 31 March 2005, and to 32,066 in the year to 31 March 2008. The figure for 2007/2008 could usefully be compared with the number of guardianships in that year (only 876). In 2007/2008, 791 of the registered powers conferred only personal welfare powers, 1,850 only financial powers, and 14,451 both welfare and financial powers. In 2001/2002, 29% of powers of attorney registered concerned personal matters, in 2003/2004 the number had risen to 48%, and now it is 82%. 80% of granters were 60 years old or more Explanatory Memorandum to Rec (2009) 11 § 29

Legal conditions for binding advance directives

- *Contents: any medical treatment including life-sustaining treatment*

Article 24 §1 a) and b) of the MCA provides that when still competent, a person may decide that if (a) at a later time and in such circumstances as he may specify, a specified treatment is proposed to be carried out or continued by a person providing health care for him, and (b) at that time he lacks capacity to consent to the carrying out or continuation of the treatment the specified treatment is not to be carried out or continued. A decision may be regarded as specifying a treatment or circumstances even though expressed in layman's term (article 24 §2). An advance directive refusing all treatment in any situation (for example, where a person explains that their decision is based on their religion or personal beliefs) may be valid and applicable.¹⁶⁴

If a patient has made an advance directive which is valid and applicable the decision has effect as he has made it at the time when the question arises whether the treatment should be carried out or continued (article 26 §1). An advance directive is legally binding on those providing treatment and failure to comply with the advance directive will result in civil liability for battery.

If a doctor is unsure of the validity or applicability of the advance directive, an application can be made to the Court of Protection and treatment can be given while the court's decision is awaited (article 26 § 4-5). A doctor will not be liable for failing to provide treatment when following an advance directive reasonably believed to be valid and applicable (article 26 §3).

The advance directive will not be applicable 'if there are reasonable grounds for believing that circumstances exist which (the individual) did not anticipate at the time of the advance decision and which would have affected his decision had he anticipated them' (article 25 § 4 c). The advance directive is not valid if the patient has done anything else clearly inconsistent with the advance directive (article 25 §2).

- *Formal aspects*

The MCA does not impose any formality and a valid advance directive could, in theory, be created by a casual chat with friends or relatives.¹⁶⁵ However, if the advance directive refuses life-sustaining treatment, it must be in writing and signed by the patient or by any other person in the presence of the patient and at the patient's direction (article 25 §5). The patient must sign or acknowledge the document in presence of a witness who must sign it (or acknowledge his signature) in the patient's presence (article 25 §6). Article 4 § 10 states that life-sustaining treatment is treatment which a healthcare professional who is providing care to the person regards as necessary to sustain life. This decision will not just depend on the type of treatment. It will also depend on the circumstances in which the healthcare professional is giving it. For example, in some situations antibiotics may be life-sustaining, but in others they can be used to treat conditions that do not threaten life.¹⁶⁶

Any advance directive may be withdrawn or altered at any time while the individual remains competent (article 24 §3). Withdrawal or alteration need not be in writing (article 24 §5).

- *Validity in time*

The MCA does not provide for a time limit. In principle, a directive drafted 50 years ago could be as effective as the one drafted last week.¹⁶⁷ Anyone who has made an advance decision is advised to regularly review and update it as necessary. Decisions made a long time in advance are not automatically invalid or inapplicable, but they may raise doubts when deciding whether they are valid and applicable. A written decision that is regularly reviewed is more likely to be valid and applicable to current circumstances – particularly for progressive illnesses. This is because it is more

¹⁶⁴ Mental Capacity Act Code of Practice §9.13

¹⁶⁵ A.R.Maclean, 'Advance directives and the rocky waters of anticipatory decision-making', *Medical Law Review*, 2008, 10.

¹⁶⁶ Mental Capacity Act Code of Practice §9.25

¹⁶⁷ A.R.Maclean, 'Advance directives and the rocky waters of anticipatory decision-making', *Medical Law Review*, 2008, 17.

likely to have taken on board changes that have occurred in a person's life since they made their decision.¹⁶⁸

- *Documentation and registration*

It is recommended that people who are thinking about making an advance decision get advice from healthcare professionals (for example, their GP or the person most closely involved with current healthcare or treatment). Healthcare professionals should record details of any discussion on healthcare records.¹⁶⁹ A written document can be evidence of an advance directive. It is helpful to tell others that the document exists and where it is. A person may want to carry it with them in case of emergency, or carry a card, bracelet or other indication that they have made an advance decision and explaining where it is kept.¹⁷⁰ Where possible, healthcare professionals should record a verbal advance decision to refuse treatment in a person's healthcare record.¹⁷¹

It is the responsibility of the person making the advance decision to make sure their decision will be drawn to the attention of healthcare professionals when it is needed.

Healthcare professionals should not delay emergency treatment to look for an advance decision if there is no clear indication that one exists. But if it is clear that a person has made an advance decision that is likely to be relevant, healthcare professionals should assess its validity and applicability as soon as possible. Sometimes the urgency of treatment decisions will make this difficult.¹⁷²

Durable powers of attorney in health matters¹⁷³

The MCA Act 2005 allows (for the first time in English law) for the appointment of a health care proxy, known as a 'lasting power of attorney'.

This appointment can be made by a competent adult (i.e. someone aged 18 years or over who is mentally capable) and it must comply with various formal requirements e.g. made in writing, witnessed, lodged with the Office of the Public Guardian. In health care matters, the donee's authority can be general or limited to specific matters, but it does not authorise the attorney to consent to or refuse life-sustaining treatment (which in the view of the person providing healthcare is necessary to sustain life) unless there is express provision to this effect in the formal document. The attorney's consent should be sought as if he was the (competent) patient, although the attorney is required to make their decisions in the best interests of the patient.

Representation by the relatives

In English law the relatives of an incompetent patient have no authority to represent him.

¹⁶⁸ Mental Capacity Act Code of Practice §9.29.

¹⁶⁹ Mental Capacity Act Code of Practice §9.14.

¹⁷⁰ Mental Capacity Act Code of Practice §9.18.

¹⁷¹ Mental Capacity Act Code of Practice §9.23.

¹⁷² Mental Capacity Act Code of Practice §9.56.

¹⁷³ R.Huxtable and A.Slowther, 'U.K.' in *Advance directives: towards a coordinated European perspective*, Zürich, Institute for Biomedical Ethics, June 2008, 98; J.Samanta, 'Lasting powers of attorney for health care under the Mental Capacity Act 2005: enhanced prospective self-determination for future incapacity or a simulacrum?' *Medical Law Review*, 2009, 377-409.

3. The use of Advance Care Planning and Advance Directives for people with dementia in clinical practice.

Advance care planning (ACP) is being promoted internationally as an effective strategy to improve end-of-life care for people with dementia. ACP is a process of communication, discussion, consultation and decision making between an individual, her/his care providers (informal and formal) and other possible relevant persons (relatives, proxy, ...) concerning future care and treatment options for that individual. Aspects of advance care planning include opening the conversation, explore options, identify wishes and preferences, decide about specific treatment, ask someone to speak for you or appoint someone to make decisions (proxy), let people know your views, preferences and wishes.¹⁷⁴

3.1 Barriers and facilitators

The application of ACP in clinical and care practice differs widely from country to country. According to a recent literature review, ACP programs have been established in parts of the US, Australia and Canada, while it is less advanced in Europe and the UK.¹⁷⁵ This is manifestly illustrated by two recent studies collecting data on the incidence of ACP among persons with cognitive impairment. Researchers from the University of Pittsburg observed that 39% of 127 persons diagnosed with mild cognitive impairment or Alzheimer's disease in a US memory disorders clinic had initiated ACP within 5 years after the diagnosis.¹⁷⁶ In contrast, a recent survey among nursing homes in the northern part of Belgium noticed that among 764 deceased residents with dementia, advance patient directives or legal representative designations were only present in respectively 3% and 8%. On the other hand, orders from the general practitioner about future care and end-of-life issues were present in 59%.¹⁷⁷ Despite the limited literature on ACP in dementia and the little clear evidence on the best way to approach ACP in people with dementia, Denning et al. identified in this review paper several themes which revealed both barriers to and facilitators for ACP that need further consideration:¹⁷⁸

- *Several studies used the mini-mental state examination (MMSE) to indicate a threshold for when a person has capacity to make ACP decisions. An MMSE score of 18-20 appeared to be a consistent threshold score required to make an advanced care plan. Below this threshold an increase of caregiver involvement in medical decision making and a decrease in patient involvement was observed. Others argue, however, that a MMSE threshold is not in keeping with the principles of determining capacity enshrined in for example the UK Mental Capacity Act 2005. A presumption of capacity requires a functional approach, is decision-specific, and requires the asking of questions that are directly relevant to the decision in question;*
- *Professionals and family carers may anticipate an adverse reaction to pursuing ACP with the person with dementia. But this is not necessarily the case in practice. The concerns of family*

¹⁷⁴ NHS Gloucestershire's Planning for your future care. Advance Care Planning. 29 March 2011. <http://www.endoflifecare.nhs.uk/download.ashx?mid=3048&nid=3050>

¹⁷⁵ Denning KH, Jones L, Sampson EL. Advance care planning for people with dementia: a review. *Int Psychogeriatr.* 2011 Dec;23(10):1535-51.

¹⁷⁶ Garand L, Dew MA, Lingler JH, DeKosky ST. Incidence and predictors of advance care planning among persons with cognitive impairment. *Am J Geriatr Psychiatry.* 2011 Aug;19(8):712-20.

¹⁷⁷ Vandervoort A, van den Block L, van der Steen JT, Vander Stichele R, Bilsen J, Deliens L. Advance directives and physicians' orders in nursing home residents with dementia in Flanders, Belgium: prevalence and associated outcomes. *Int Psychogeriatr.* 2012 Jul;24(7):1133-43.

¹⁷⁸ Denning KH, Jones L, Sampson EL. Advance care planning for people with dementia: a review. *Int Psychogeriatr.* 2011 Dec;23(10):1535-51.

carers seem to be unfounded and most often the person with dementia did not show distress, either before or after the discussions;

- *Family caregivers are in general unprepared for making decisions when older people with dementia are deemed no longer able to make decisions about their care and treatment. Several studies indicate that the burdensome effects of the illness on the family caregiver – feelings of guilt, a sense of failure when the person with dementia has to move to residential care, lack of information on the disease nature, trajectory and prognosis – combined with the lack of knowledge on palliative and end-of-life care, leaves family carers unprepared to make effective decisions on (future) care issues and end-of-life care on behalf of their relative;*
- *When considering professional attitudes, the key professional barrier to advance care planning is a lack of knowledge and skills in advising on issues related to developing an advance care plan, failure to discuss prognostic issues of dementia and avoidance of such discussions at a time when the person with dementia still has the cognition and the capacity to make decisions on current and advance care.*
- *Decisions about life-sustaining treatment are often presented at times of health and social care crises, and therefore at times of great distress for carers. Hence it may be difficult to be certain that the choices made on behalf of the person with dementia will genuinely reflect their preferences. Family carers are in general more likely to opt for treatments rather than to abnegate them. Furthermore, family carers may be divided as to whether they are motivated by what they 'believe' the person with dementia would have wanted as against what would be in their best interests in the circumstances.*

Dening et al. conclude that a key facilitator to ACP for persons with dementia is “a dedicated professional available to educate families about ACP but also other health professionals.” A key barrier “is the potential for proxy decision-makers to influence end-of-life care that may not reflect the wishes of the person with dementia.”

3.2 Effectiveness of ACP

Although, the current international evidence base on the effectiveness of advance care planning in dementia is even more limited, there is some evidence – albeit of variable quality – which shows that ACP has the potential to reduce inappropriate hospital admissions and healthcare costs for people with cognitive impairment and dementia.¹⁷⁹

For example the previously mentioned survey in Belgian nursing homes showed that the presence of a general practitioner's order was positively associated with receiving specialist palliative care in the nursing home and resulted in a lower chance of dying in a hospital.¹⁸⁰ There is also evidence that targeted end-of-life care education and a supportive ACP program for both relatives and professionals reduces health care services utilization and hospital admissions, without affecting satisfaction or mortality.^{181 182}

¹⁷⁹ Robinson L, Dickinson C, Rousseau N, Beyer F, Clark A, Hughes J, Howel D, Exley C. A systematic review of the effectiveness of advance care planning interventions for people with cognitive impairment and dementia. *Age Ageing*. 2012 Mar;41(2):263-9.

¹⁸⁰ Vandervoort A, van den Block L, van der Steen JT, Vander Stichele R, Bilsen J, Deliens L. Advance directives and physicians' orders in nursing home residents with dementia in Flanders, Belgium: prevalence and associated outcomes. *Int Psychogeriatr*. 2012 Jul;24(7):1133-43.

¹⁸¹ Molloy DW, Guyatt GH, Russo R, Goeree R, O'Brien BJ, Bédard M, Willan A, Watson J, Patterson C, Harrison C, Standish T, Strang D, Darzins PJ, Smith S, Dubois S. Systematic implementation of an advance directive program in nursing homes: a randomized controlled trial. *JAMA*. 2000 Mar 15;283(11):1437-44.

¹⁸² Caplan GA, Meller A, Squires B, Chan S, Willett W. Advance care planning and hospital in the nursing home. *Age Ageing*. 2006 Nov;35(6):581-5.

But obviously, further high-quality research is needed to strengthen the argument for ACP to become an evidence-based part of routine dementia care. It must be acknowledged, however, that this is a difficult and challenging area in which to carry out randomised controlled trials.

3.3 Tools, instruments and pilot projects

There is also a lack of tools and instruments to guide and support advance care planning in persons with dementia. A promising instrument to support the process of ACP in older people and persons with dementia might be the Palliative and Therapeutic Harmonization (PATH) model, developed at the Dalhousie University in Halifax (Canada).¹⁸³ The model provides a structured approach that places frailty at the forefront of medical and surgical decision-making in older adults. The PATH process uses the Clinical Frailty Scale (CFS) as the starting point from which to consider the likelihood of various outcomes. The PATH process facilitates current and future health decisions in older adults with multiple health concerns.

The model divides the decision-making process into three clinical encounters taking place one to two weeks apart. This allows time for the decision-maker to review and reflect. During the PATH process, special attention is given to dementia, as dementia is critically important to decision-making and not recognizing dementia may result in unsuitable care. Therefore the need for a caregiver or substitute decision-maker may be needed during the PATH process.

Although present outcome measures are still limited, the model has demonstrated feasibility through implementation in multiple care environments. Evaluation of the effect of PATH on appropriateness of care in long-term care is underway. Lastly, a multicenter, randomized controlled study is needed to demonstrate the effectiveness of the model.

A growing number of individual initiatives from health, care, patients or societal organizations in various EU Member States are aimed at developing instruments for advance care planning specifically aimed at persons with dementia, their family caregivers and/or their professional caregivers. These instruments vary from inquiry forms allowing people to express their will concerning future care to information brochures or procedures for good practice in hospitals and nursing homes.

An example is the NHS Gloucestershire's 'Planning for your future care' booklet.¹⁸⁴ This guide, adapted from the Weston Hospicecare Advance Care Plan and Preferred Priorities for Care guidelines, covers fields as preparing for the future, assisting with practical arrangements and enabling the right care to be given at the right time. Other examples are the Finnish Alzheimer Society who has developed a form for an advance directive based on the guidelines from Alzheimer Europe¹⁸⁵; the Alzheimer's Society in the UK developed documents for granting a power of attorney¹⁸⁶ and advance decisions¹⁸⁷; while the Belgian King Baudouin Foundation supports 11 pilot projects on the application of advance care planning for persons with dementia in various care settings.¹⁸⁸

¹⁸³ Moorhouse P, Mallery LH. Palliative and therapeutic harmonization: a model for appropriate decision-making in frail older adults. *J Am Geriatr Soc.* 2012 Dec;60(12):2326-32.

¹⁸⁴ NHS Gloucestershire's Planning for your future care. *Advance Care Planning.* 29 March 2011. <http://www.endoflifecare.nhs.uk/download.ashx?mid=3048&nid=3050>

¹⁸⁵ Finnish Alzheimer Society. Hoitotahtoni, www.muistiliitto.fi/document.php?DOC_ID=965&SEC=f7572d2a37f111813c61c0fd85348b44.

¹⁸⁶ Alzheimer's Society. Enduring Power of Attorney and Lasting Powers of Attorney. http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=154

¹⁸⁷ Alzheimer's Society. Advance Decision. http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=143

¹⁸⁸ King Baudouin Foundation. Pilot projects 'Vroeger nadenken ... over later: Vroegtijdige zorgplanning voor personen met demencie - Oproep voor pilootprojecten - Penser plus tôt ... à plus tard en cas de maladie d'Alzheimer ou maladie apparentée'. <http://www.kbs-frb.be/grants.aspx?callid=300036&year=2012&langtype=2067>, <http://www.kbs-frb.be/grants.aspx?callid=300036&year=2012&langtype=2060>.

4. Conclusions & main recommendations

In Europe few people with dementia have made advance directives¹⁸⁹. They are usually associated with life-threatening diseases such as cancer or heart disease, cover emergency situations where patients have lost consciousness or refer to prolonged states of unconsciousness. The situation is different in the case of dementia. Depending on the stage at which a person is diagnosed, she/he may live for another 5 to 20 years. During this time, the mental capacity of the person concerned will gradually and progressively deteriorate and this will affect her/his ability to make decisions. At various times during the illness, situations will arise when care and treatment decisions must be made.

It is obvious that no pressure should be exerted on any individual to draw up an advance directive. Advance directives are there to support people who feel strongly to make their preferences effective. In the case of dementia, advance directives:

- *contribute to the peace of mind and to maintain a feeling of some kind of control over one's future care and treatment;*
- *offer the opportunity to express wishes about care and treatment one would like to have;*
- *offer the opportunity to protect oneself against inappropriate care and unwanted treatment;*
- *help to realise that even with a diagnosis of dementia, it is possible to make decisions about one's own life;*
- *offer an opportunity to discuss various options with the doctor;*
- *offer the opportunity to understand what certain treatments involve and perhaps allay fears.*

Advance directives are also important for formal and informal carers. They:

- *contribute to the peace of mind that the person is receiving the care and treatment (s)he would have liked and not what s(he) would have objected to;*
- *help professional carers to comply with the obligation to take into consideration the wishes of the person with dementia;*
- *help informal carers to deal with decision-making dilemmas;*
- *help to avoid conflicts between informal and formal carers about what the person living with dementia would have wanted.*¹⁹⁰

Ideally advance directives are part of an ongoing process and dialogue with relatives, doctors and other caregivers. This is best achieved within the broader context of advance care planning¹⁹¹. Advance care planning is a structured way to initiate and maintain a dialogue about future care. It is a process of communication, consultation and decision-making between a person, his or her carers and other relevant persons (relatives, proxy, etc.) concerning future (health) care options. Aspects of advance care planning include opening the conversation, exploring options, identifying wishes and preferences, deciding about specific treatment, asking someone to speak for you or appointing someone to make decisions (proxy) on your behalf, and letting people know your views, preferences and wishes. In some countries guidelines for the implementation of advance care plans have been published¹⁹². According to the NHS Guide on this topic, aspects of advance care planning include: opening the conversation, exploring options, identifying wishes and preferences, deciding about specific treatment, asking someone to speak for you or appointing someone to make decisions (proxy) on your behalf, and letting people know your views, preferences and wishes. The wish to make an advance care plan as well as including general wishes concerning care can be part of an

¹⁸⁹ See also Harrison Denning, K., Jones, L., Sampson, E.L., (2011) Advance care planning for people with dementia: a review, International psychogeriatrics

¹⁹⁰ Alzheimer Europe (2006), The use of advance directives by people with dementia, Alzheimer Europe

¹⁹¹ Nuffield Council on Bioethics (2009) Dementia, ethical issues

¹⁹² E.g. NHS guide (2012) Planning for your future care

advance directive¹⁹³. In that sense advance directives and advance care plans become intertwined tools to support the autonomy of people with dementia.

Main recommendations

- **Contextual provisions of Advance Directives for persons living with dementia**

- [1] Advance directives should be part of the broader context of advance care planning.** An advance directive is a means to provide high quality care in line with the wishes and will of the person with dementia, and not a goal in itself or an end product of advance care planning. It is an opportunity for starting and maintaining a process of communication between the person living with dementia and his or her carers.
- [2] National authorities are encouraged to provide a legal framework on advance directives adapted to the specific needs of persons living with dementia.**
- [3] Proper models and good practices specifically oriented towards people living with dementia need to be implemented, further developed and disseminated,** because all stakeholders – patients, relatives, informal and formal carers, healthcare policy organisations, ... – have to be made aware of the specificities and complexities regarding advance care planning and advanced directives for people living with dementia.
- [4] The person's current attitude towards a certain treatment or a care intervention - ascertained feelings, desires and wishes - should always be taken into account, even if there is an advance directive or a designated proxy,** since there can be major changes in values and preferences between the time when persons complete their advance directive and when it comes into effect.
- [5] Although the use of advance directives should be promoted, nobody can be forced to make up an advance directive.** If a person does not want to address issues about future care and treatment or end-of-life for his- or herself, this needs to be respected.
- [6] Doctors and other healthcare professionals involved in the care of people living with dementia should be properly trained in advance care planning and the use of advance directives.**
- [7] In order to increase peoples' knowledge about advance directives and to encourage their use, the costs for drafting and registering these directives should be minimal for the person living with dementia.**

- **Content of Advance Directives for persons living with dementia**

- [8] People should be encouraged to designate a healthcare proxy in their advance directives.** This person represents the person living with dementia in making decisions on medical and care matters when the person is no longer competent to make these decisions. A healthcare proxy should be aware of the wishes, beliefs, values, preferences and decisions of the person s(he) is representing, therefore communication and deliberation between this person and the proxy is indispensable.
- [9] Advance directives are preferably accompanied by a personal statement of values containing information about what is important and meaningful in the life of the person who has drawn up the directive.**
- [10] The refusal of a specific treatment expressed in an advance directive is prima facie legally binding and should consequently be respected**
- [11] With regard to a request for a treatment in an advance directive, a healthcare professional should take this request into account, in so far as this treatment accords to professional standards.**

¹⁹³ See e.g. Finnish and Swedish Alzheimer Advance directive form (2012)
http://www.muistiliitto.fi/fin/muisti_ja_muistisairaudet/palvelut_etuudet_ja_oikeudet/hoitotahto/



- **Validity and applicability of Advance Directives for persons living with dementia**

[12] It is important to advise persons living with dementia of the possibilities of advance care planning and the use of advance directives whilst they still have the necessary competence and mental capacities to make use of them. Therefore, the importance of a timely and disclosed diagnosis needs to be underlined. Nevertheless, a sensitive approach is necessary, taking into consideration that not all persons are prepared to decide about their future.

[13] In the context of high quality care, advance directives should be integrated in all relevant patient and care records with maximal respect of privacy and confidentiality.