RIGHTS, AUTONOMY & DIGNITY OF PEOPLE WITH DEMENTIA

RIGHTS, AUTONOMY & DIGNITY OF PEOPLE LIVING WITH DEMENTIA

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CONTEXT, OBJECTIVES & METHOD

CONTEXT & OBJECTIVES

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.

- **Specific Objective :** 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.

METHOD

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-of recommendations

COMPETENCE ASSESSMENT

RESULTS [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.
- Differentiating between competence and incompetence remains difficult.
- Repeated assessment on a case by case approach is necessary.

- **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 devaluation [2] 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 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 developed [4], 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].

- **Competence assessment & advance directives:** An important question is whether patients who have been diagnosed with dementia can at that stage still make up an advance directive. The fact that capacity is frequently impaired in persons living with dementia provides reasonable grounds for doubt and prudence.
  Given the possibility of fluctuating capacity in dementia, the capacity should be carefully assessed at the time an advance directive is prepared and also before it is implemented; 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 [6].

- **Competence assessment & driving:** Contrary to competence assessment within the context of advance directives, competence assessment as regards driving is a rather strictly regulated domain in European jurisdictions. This is not a surprise as dementia and driving safety is of particular concern to society. The question arises whether the diagnosis of dementia has legal consequences regarding the license [7] to drive of the person concerned. We have looked for an answer to this question in different European jurisdictions [8].
  A preliminary condition for the competent authorities to take a measure 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 competent authorities being notified of the dementia diagnosis by the treating physician or the person him-or herself (or a relative). This notification can be either on an obligatory or a voluntary basis. If the treating physician notifies of the diagnosis (s)he can do so either with the consent of the patient or without his or her consent or even his or her knowledge. Still another distinction is notification to a health inspectorate that in turn can notify the road safety authorities of the diagnosis or the latter may be informed directly.

- **A second possibility** for informing the competent authorities of a dementia diagnosis is by submitting persons who request a driving license or to renew existing one to a health examination, be it obligatory or voluntary. With regard to the competent authorities' access to a dementia diagnosis, in all European jurisdictions a diagnosis of dementia is protected by the obligation of the treating physician to respect medical secrecy and confidentiality. 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 a health inspectorate or road safety inspectorate of each diagnosis of dementia 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 not exist for other diseases which might create risks for driving safety also, article 14 (prohibition of discrimination) would be breached. To our knowledge, no such blunt obligation to notify the competent authorities of a dementia diagnosis exists in European jurisdictions.
- **A third approach** which is more acceptable from the point of view of protecting medical secrecy and privacy consists of granting physicians the possibility of notifying the competent authorities of a diagnosis of dementia or any other medical condition that may create a risk for safe driving. This possibility of notifying authorities while respecting medical secrecy concerning a diagnosis of dementia may create a danger for the person himself or herself, or even third persons, because the patient may continue to drive despite there being evidence that he or she 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'. 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) of a diagnosis of dementia.
- **A fourth approach** consists in legally obliging the treating physician to inform and warn the person living with dementia of the risk that a cognitive impairment may affect his ability to drive. It is then that person's responsibility to inform the relevant authorities because the obligation to respect medical secrecy prevents the physician to inform the competent authorities. This solution lays the responsibility to inform the competent authorities entirely upon the person living with dementia or his relatives and may create a false feeling of reassurance because the treating physician has no means to control whether notification by the person has been made or not.

Next to notification in one or another way, 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. In this way no one is discriminated against. A disadvantage may be that this is probably a very costly procedure. Another option is to limit the validity of a driving license until a certain age and make its renewal dependent upon a medical examination.

Once they are informed in one or another way that a diagnosis of dementia has been made, authorities responsible for safe driving such as the police can react in different ways. 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 autonomy and privacy (article 8 European Convention on Human Rights) would oppose such an automatic measure. Nonetheless, there are countries where measures exist that may have this result. Another possibility is to oblige the treating physician to recommend the person living with dementia to stop driving. If the person 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. In other countries a diagnosis of dementia may be followed by a medical examination in order to control the ability of the person to drive.

CONCLUSIONS & MAIN RECOMMENDATIONS

Competence Assessment for people 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 living 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 no longer has capacity for decision-making, 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 but not all, 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.**

ADVANCE DIRECTIVES

RESULTS [9]

- **Introduction:** Advance directives are written or oral statements that are intended to govern healthcare and related decision-making for their authors, for both positive (consent) and negative (refusal) decisions, should they lose decisional capacity in the future. The basis for the moral (and legal) validity of advance directives is the person's right to autonomy or to self-determination, regardless of his/her current cognitive capacity and capacity to express wishes. The aim of advance directives in the context of advance care planning for a person living with dementia is to clarify this person's wishes and will concerning his/her future in the light of an anticipated decline of the capacity to make decisions and/or of the ability to express these towards others. Advance directives may or may not include end-of-life decisions.

- **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.

The legal validity of advance directives is recognised in 22 Member States of the European Union.
There is no obligation to make an advance directive.

- **Mapping of national regulations on advance directives:** The legal status of advance directives is a complex issue as many elements have to be considered. One of these is the Biomedicine Convention of the Council of Europe (Oviedo, 1997). The ratification of this Convention has important legal consequences and mitigates the distinction between states that have enacted specific legislation on advance directives and states that have not enacted specific legislation but that have ratified the Convention.

  - **Countries with specific legislation regarding advance directives (Table 1)**
    Some interesting conclusions can be drawn from Table 1. Regulating advance directives is a (very) recent phenomenon in Europe. Ten of the 15 laws were approved after 2005. Only two are dated before 2000. Nine countries have ratified the Biomedicine Convention while six did not ratify. In only one country the refusal of a treatment is not binding. In the other countries an advance directive that contains a refusal is prima facie binding but there are important differences between the countries. In different countries only refusals of treatment by terminally ill patients are binding while in all other cases refusals are not binding. In other countries a refusal is binding but may be overruled by physicians when there are good reasons to do so. And still other countries have limited the validity in time of an advance directive. Such a limit may vary between 2 to 5 years. The question arises as to what the exact legal consequences are when a person living with dementia who has drawn up a valid advance directive subsequently becomes incompetent, and therefore unable, to confirm its validity when this period of validity has expired. One possible consequence is that this person may no longer have a valid advance directive. In practice, this would mean that most persons living with dementia could only have a

valid advance directive for a period where they are still competent to make decisions, in other words, when they do not need an advance directive. A more useful interpretation of the consequence of the limitation in time is that the advance directive has to be confirmed when this period of time has expired in order to stay valid when the author still has the competence to do so. However, if the author has become incompetent in the meantime, the advance directive remains valid and this time for an undetermined period. It goes without saying that the older such an advance directive is, the less likely it will be considered as prima facie binding.

Table 1. Countries with specific legislation regarding advance directives

COUNTRY	YEAR OF LAW	REFUSAL OF TREATMENT BINDING OR NOT	BIOMEDICINE CONVENTION RATIFIED OR NOT
1. Austria	2006	Yes (limited to 5 y)	No
2. Belgium	2002	Yes (No time limit)	No
3. Denmark	1998	Yes, terminally ill - No in other cases	Yes (1999)
4. Estonia	2001	Text law not clear	Yes (2002)
5. Finland	2005	Yes, emergency treatment - No in other cases	Yes (2010)
6. France	2005	No (limited to 3y)	Yes (2012)
7. Germany	2009	Yes (no time limit)	No
8. Hungary	2009	Yes (limited to 2y)	Yes (2002)
9. Latvia	2009	Yes (no time limit)	Yes (2010)
10. Luxembourg	2009	In principle; unless good reasons	No
11. Netherlands	1994	In principle; not if good reasons	No
12. Portugal	2012	Yes (limited to 5 y)	Yes (2001)
13. Slovenia	2007	Yes, terminally ill - No in other cases	Yes (1999)
14. Spain	2002	In principle; not if against good medical practice	Yes (2000)
15. United Kingdom	2005	Yes	No

- **Advance directives & the Biomedicine Convention**

Article 9 of the Convention relates to previously expressed wishes and provides the following: '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. It is not clear what is to be understood by 'taken 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. In this respect it is relevant to refer to article 27 of this Convention that provides that: '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 Member States to give patients wider protection by providing that an advance directive has to be respected under certain conditions.

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 helpful 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')". 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 although there is no specific regulation of advance directives in that country. This conclusion mitigates of course the importance of the distinction between countries that dispose of specific legislation of advance directives and those that haven't but have ratified the Biomedicine Convention. Table 2 gives an overview of the status of the Biomedicine Convention in the countries without specific legislation on advance directives.

Table 2. Countries without specific legislation regarding advance directives

COUNTRY	BIOMEDICINE CONVENTION RATIFIED OR NOT
1. Bulgaria	Yes (2003)
2. Cyprus	Yes (2001)
3. Czech Republic	Yes (2001)
4. Greece	Yes (1999)
5. Ireland	No
6. Italy	No
7. Lithuania	Yes (2003)
8. Malta	No
9. Poland	No
10. Romania	Yes (2001)
11. Slovakia	Yes (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 (Table 1) 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 which have not yet ratified the Biomedicine Convention are in the process of approving specific legislation: Ireland and Italy.

- **Advance directives & persons living with dementia:** The ethical and legal questions raised by advance directives have a general character, regardless of the specific type of disease. However we will focus here on some specific issues relating to dementia.

  - **Ethical issues: continuity and foreseeability**

    In ethical and legal terms, so called continuity of the person is a necessary condition for the validity of an advance directive. In other words, the instructions contained in an advance directive may only be carried out if the person living with dementia by implementation is the same person as the author of the directive. This requirement may appear to be trivial. However, with regard to dementia, doubts have been expressed as to whether such continuity is in fact present. Much philosophical discussion exists about the relationship between the 'then' self that existed prior to the onset of dementia and the 'now' self that lives almost entirely in the present without any connection to the past. Proponents of the 'precedent autonomy or critical interest' approach underline the stewardship responsibility of the 'then' self for the journey into forgetfulness. As a consequence, post-dementia decisions should be based on historical lifetime values and beliefs. Proponents of the 'experiential interest approach' argue that there can be major changes in values between the time when persons complete their advance directive and when it comes into effect.

    This led them to propose that the person with predementia and the person living with dementia are two different people. Even if persons living with dementia might be incompetent, they still have the capacity to experience their life and the context wherein it is embedded. Hence, according to the experiential interest approach, contemporary preferences, needs, and desires, coupled with the present well-being of the person living with dementia should be the main area for substituted decision-making. It could thus be concluded that an advance directive has no claim to be strictly binding in cases of dementia.

    A different view can be taken from a practical and legal point of view. In every jurisdiction the law always assumes continuity of the person, irrespective of illness or change of personality. Without wishing to settle these controversies, the facts of bodily identity, and, in particular, social connections, provide important grounds for considering the person as the same person throughout the full course of the illness [10].

    Another point of controversy is whether it is possible to imagine the life of a person with dementia. Some people therefore deny that a person living with dementia can draw up an advance directive. 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 older people. Their experiences with their own illnesses and those of others 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. Moreover a person confronted with early-stage dementia retains mental capacity. His initial experience of the disease and his knowledge regarding its likely course allow him to draw up a well-grounded advance directive [11].

Against this background, the rights of people with dementia to play their part in medical decision-making with the aid of an advance directive should be supported.

- **Advance directives and advance care planning**

  In Europe few people with dementia have made advance directives [12]. 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 his or her 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 [13].

  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 planning [14]. 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 published [15]. 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 advance directive [16]. In that sense advance directives and advance care plans become intertwined tools to support the autonomy of people with dementia.

CONCLUSIONS & 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 living 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 people 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 people 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.**

Validity and applicability of Advance Directives for people 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.**

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