



Advance directives

A position paper – 6/2005

A. Executive summary

1. The present paper constitutes the input of Alzheimer Europe and its member organisations to the ongoing discussions within Europe about advance directives (in the context of Alzheimer's disease and other forms of dementia). It is the result of discussions carried out in a multidisciplinary group, comprising experts in the field of psychiatry, neurology, pharmacology, psychology, law and ethics, in collaboration with the Board of Alzheimer Europe and its member associations. Please see Annex 1 for the list of participants of the working group.
2. Alzheimer Europe's position on advance directives was guided by several general principles and was influenced by principles contained in pre-existing European or international documents. Please refer to section D for details.
3. On the basis of these principles and of a review of current literature concerning issues linked to the use of advance directives, Alzheimer Europe has developed the following position with regard to advance directives.
 - a) Alzheimer Europe would like to promote the use of advance directives for decisions covering a wide range of health related issues e.g. treatment, care, welfare, research, the appointment of health care proxies etc.
 - b) Alzheimer Europe supports the concept of health care proxies and encourages governments to legally recognise their role and also to develop the relevant safeguards for their involvement in the decision-making process.
 - c) Alzheimer Europe would like to emphasise the importance of involving doctors and other qualified health care professionals when considering whether/how to draw up an advance directive within the context of advance care planning.
 - d) Due to difficulties in obtaining an appropriate level of precision (which is neither too vague nor too specific to be of practical use), Alzheimer Europe encourages people to write statements of values.
 - e) Alzheimer Europe expects governments to set up appropriate systems for the registration, use and review of advance directives.
 - f) Alzheimer Europe is of the opinion that for an advance directive to be valid, certain generally accepted criteria should be fulfilled e.g. that the person has the necessary and relevant capacity, is free from undue pressure, has not made a more recent version and has stated wishes that are applicable to the current situation/proposed treatment.
 - g) With regard to debates surrounding the issue of current versus formerly expressed wishes, Alzheimer Europe insists on the importance of always trying to ascertain the wishes of patients even if they have written an advance directive. If the person is fully competent, doctors should not follow instructions/wishes expressed in the advance directive. If the person is not fully competent and there

appears to be a conflict between current and former wishes, the person's current wishes and feelings should be considered alongside those expressed in the advance directive as they represent the person's current mental and emotional state and attitudes.

- h) Decisions not to comply with valid advance directives should be documented in the patients' medical files and an explanation should be given to significant others, relevant supervisory bodies and health care proxies.
- i) In order to guarantee equity in the provision of health care and to ensure that people have a real choice, Alzheimer Europe emphasises the need to increase the availability and improve the quality of palliative care services/facilities.
- j) Alzheimer Europe urges governments to provide a clear statutory basis for effective advance directives with appropriate safeguards and a framework of procedures to ensure their effectiveness.

A growing number of its members consider that governments should legally recognise advance directives and make refusals of treatment expressed in advance directives legally binding albeit with adequate safeguards.

- 4. For references and more detailed information about the points raised in this position paper, please refer to the background information document which is freely available from Alzheimer Europe's head office (Alzheimer Europe, 145 route de Thionville, L-2611 Luxembourg) and can be consulted on the Alzheimer Europe website (<http://www.alzheimer-europe.org>).

B. Introduction

- 5. **Decision-making in the early stages of the disease.** Most forms of dementia involve the gradual and irreversible deterioration of cognitive abilities (e.g. memory, language and thinking etc.). An early diagnosis of Alzheimer's disease may enable the person concerned to benefit from medication which treats global symptoms and is most effective in the early to mid stages of the disease. In the early stages, it is still possible for the person with dementia to make decisions concerning their finances, personal welfare, medical treatment and possible participation in research.
- 6. **Respect for autonomy and human dignity.** Alzheimer Europe therefore feels that it is important that people with dementia are given the opportunity to exercise their right to self-determination and is of the opinion that advance statements and directives are an effective means of preserving the autonomy of people with dementia and reflecting their human dignity.
- 7. **Use of terms:**
 - a) **Advance statement** is a **general term** covering any statement a person may wish to make about future decision-making. This may be a statement of principles, a statement of preferences or dislikes, or refer to a specific decision (e.g. regarding a specific nursing home or doctor). It can be positive, negative or neutral. The term encompasses advance directives.
 - b) **Advance directive** is a **more specific** term relating to particular decisions or types of decisions, particularly regarding medical treatment and health care that may have to be made in the future. Although usually a negative advance directive (also termed an *advance refusal*), it can also be positive.

In some countries, the term is used to refer to a document consisting of two parts:

1. **instructions/requests** concerning medical treatment and/or health care;
2. **a proxy form** (sometimes referred to as a **medical power of attorney** or **health care proxy**), which lets a person name someone to make decisions about their medical treatment or health care on their behalf. However, the two possibilities need to be thought about separately. It is possible but not necessary to complete both parts of the document.

c) **Living wills.** Advance directives are sometimes referred to as *living wills*.

For the purposes of this document, we will use the term **advance directive** or **advance statement** depending on the context.

8. **Early diagnosis and disclosure.** People with dementia have a real opportunity to exercise their right to self-determination in this way with regard to the management of their condition only, if they are aware of that condition at a sufficiently early stage. This underlines the importance of an early diagnosis and disclosure of the diagnosis to the person with dementia. In addition, people should be provided with information about the implications of the diagnosis and the prognosis. Face-to-face discussions should be backed up by written material.

It is important to inform people about advance directives whilst they still have the necessary capacity to write one, should they eventually decide to do so. Later on in the illness forward planning becomes impossible because of the progressive impairment which is central to dementia. Alzheimer Europe and its member organisations wish to emphasise the importance of this issue.

9. **Legal recognition of advance directives.** For an advance directive to serve the purpose for which it was intended, it needs to be legally recognised, readily available when needed and legally effective. Although some governments have recognised the need to clarify the legal status of advance directives and have legislated in this domain, others are lagging well behind.

Alzheimer Europe therefore urges governments and their legislators:

- to legally recognise advance directives,
- to provide guidance on their use and
- to set up a registration system.

Alzheimer Europe and its member organisations also recognise their own role in raising awareness of advance directives.

10. **Advance care planning.** Alzheimer Europe would like to put the writing of advance directives in the context of advance care planning in general. For people with dementia, this can be seen as a global approach to future health care and welfare involving reflection, discussion and communication of treatment and care preferences throughout the course of the disease and also at the end of life. Advance care planning may or may not lead to the writing of an advance directive. We would like to stress that no one should be forced or put under any pressure to write an advance directive. If somebody does not want to address such issues and prefers to let others decide on their behalf, their choice should be respected.
11. **Points to consider and guiding principles.** Before discussing the scope of advance directives and certain practical and legal issues, we would like to clarify a few points concerning the use of advance directives specifically for people with dementia. Furthermore, we would like to stress the absolute necessity to improve the provision of palliative care. Finally, an outline of some of the guiding principles behind this position paper will be provided.

C. Clarification on the use of advance directives in the case of dementia

12. **Advance directives and end-of-life decisions.** Advance directives are usually associated with life-threatening illnesses such as cancer or heart disease. They also cover emergency situations where patients have lost consciousness or refer to prolonged states of unconsciousness e.g. persistent vegetative state. In such cases, the provisions contained in the advance directive usually concern end-of-life decisions. Indeed, the concept of the advance directive, which was pioneered by Luis Kutner and others in the late 1960s¹, was to give people the opportunity to express the sentiment that when death is near and unavoidable, dignity and comfort should take precedence over efforts to prolong life and postpone death which are considered unlikely to enhance quality of life in the last moments of a person's life.
13. **Issues concerning advance directives in the case of dementia.** The situation is somewhat different in the case of dementia. Depending on the stage at which a person is diagnosed, they may live with the disease from that point on for anything from about 5 to 20 years. During this time, the mental capacity of people with Alzheimer's disease and some other forms of dementia will gradually and progressively deteriorate and this will affect their ability to make decisions. In the early stages, people with dementia can still make some decisions but not others. As the disease progresses, the ability to make decisions will deteriorate although people may still be able to participate in the decision-making process to some extent. Eventually, there may come a time when they will no longer be able to make any decisions. At various times during the illness, situations will most probably arise when healthcare decisions must be made. It should therefore be possible for advance directives to cover a long period of time when the person has partial capacity and not be limited to end-of-life decisions. For these reasons, Alzheimer Europe supports the development of advance directives specifically for people with dementia.
14. **Withdrawal or non-application of life-saving or life-sustaining treatment.** Although an advance directive may contain wishes linked to the withdrawal or non-application of life-saving or life-sustaining treatment, Alzheimer Europe would like to emphasise that the use of advance directives to request assisted suicide or active voluntary euthanasia raises important ethical issues that are beyond the scope of this document and which may be particularly complicated in the case of dementia. A major difference between active euthanasia and the withdrawal of life-sustaining treatment is that the aim of the former is to cause death whereas the aim of the latter is to stop a treatment which no longer has any chance of being of benefit to the patient's condition and/or may be causing undesirable side effects or risks to the patient. Furthermore, it should be noted that in the vast majority of countries, a request in an advance directive for active euthanasia would not be considered valid.
15. **Statements concerning the refusal of treatment and the prolongation of life.** Whereas some people are concerned about the overuse of medical treatment (i.e. when there is no hope of improvement or recovery), others fear that they will *not* be given the treatment they need at a time when they are unable to speak for themselves. Alzheimer Europe would like to ensure that advance directives in the case of dementia are not focused only on refusal of treatment. A person must be equally supported and encouraged to express a wish to receive whatever form of appropriate medical treatment and/or care is available to prolong their life.

¹ Maude, B. et al. (2004), Advance Medical Directives (living will, power of attorney and health care proxy) (Internet article: retrieved 31/3/2005 – http://www.aidsmart.com/ResourceDetails.cfm?Article_id=7814&ArticleType=NEWS)

D. Guiding principles

16. **Recommendations on the legal rights and protection of adults with incapacity.** At its Annual General Meeting in Munich on 15 October 2000, Alzheimer Europe adopted recommendations on how to improve the legal rights and protection of adults with incapacity due to dementia. This included a section on bioethical issues. These recommendations obviously need to guide any response of the organisation regarding advance directives.
- a) Every person diagnosed with dementia should have the right to be informed of the diagnosis as soon as possible. (§6)
 - b) The autonomy of the person with dementia should be respected at all times. As long as s/he maintains the ability to make decisions concerning his/her life, such decisions should be sought, respected and given priority over any proxy decision maker. Indeed, irrespective of the level of capacity of the person with dementia, his/her interests must always come first. There should always be an assumption in favour of capacity and of involvement and choice. (§7)
 - c) People with dementia should be informed about the advantages of writing an advance directive and appointing a guardian/lawful representative (preferably, but not necessarily together). The necessary structures or facilities should be put into place by governments to ensure that this is possible. (§8)
 - d) Alzheimer Europe has written an advance directive which is available in all the official languages of the European Union². We recommend, however, that people seek guidance from a doctor in order to ensure that the advance directive is clear and in line with modern practice. It is also necessary to ensure that the person writing the advance directive is aware of the consequences of his/her choices and that s/he has sufficient capacity to write such a document. In order to ensure that advance directives are respected, we recommend that legal representatives and medical professionals be obliged to take into consideration wishes expressed in such documents. Failure to do so should require valid justification. Furthermore, we recommend the setting up of a national register of advance directives, the creation of cooperation between countries and the inclusion of details about the advance directive in existing computerised medical files (subject to respect for national laws on data protection). (§9)
 - e) It is important to ensure that at all stages, as well as when the person with dementia approaches the end of his/her life, his/her rights are respected and his/her dignity maintained. Certain decisions which need to be taken at the end of a person's life cannot be easily taken by someone else e.g. concerning resuscitation, life-prolonging treatment, the use of certain forms of harsh or invasive treatment or painkillers and the provision of palliative care. Such decisions should therefore ideally be noted in an advance directive. This should be clearly recorded in the person's medical file. (§19)
17. **General principles.** The following general principles should also be borne in mind:
- a) A person with dementia remains a full person regardless of the severity of the disease or the degree of cognitive decline. Alzheimer Europe does not adhere to any theory which denies people with dementia "personhood" i.e. which implies or states that a person lacking capacity is in some way not a person. The person with dementia should always be treated with respect and consideration.
 - b) The autonomy of the person with dementia should be respected at all times, although other principles such as beneficence, justice and non-maleficence should also be borne in mind and balanced with respect for the person's right to self-determination.

² The advance directive is available in the official languages of the European Union before enlargement i.e. Danish, Dutch, English, Finnish, French, German, Greek, Italian, Portuguese, Spanish and Swedish.

- c) Capacity is not an all-or-none phenomenon. We believe that it should always be considered and assessed in relation to specific decisions or categories of decision (the person is deemed capable or incapable of decision A or decision B, etc.). In addition, capacity can be partial. In dementia a person does not usually *suddenly* lose the capacity to decide about something, but *gradually* loses it. In many forms of dementia, furthermore, a person's capacity to make certain decisions may fluctuate with time. For all these reasons, capacity should be assessed on a case by case basis, in relation to specific areas of decision-making, and taking into account the overall condition of the person.
 - d) It must be recognised that many legal provisions on proxy decision-making, whether by guardians, courts or other means, have traditionally depended on an all-or-none view of capacity, though new laws in a number of countries are attempting to provide a more flexible and graduated approach to incapacity.
 - e) Alzheimer Europe recognises the need to include people with dementia in the early to late stages of the disease in research, albeit with the necessary prior and current consent, and the existence of adequate safeguards. It is important to find the right balance between the protection of people with dementia and their right to decide whether to participate in such research (please see paragraphs 31 to 33 for more information).
18. **Other principles from pre-existing European or international documents.** In drafting this position paper on advance directives, the above principles as well as the Declaration on the Promotion of Patients' Rights in Europe (WHO, 1994), the Council of Europe's Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (Oviedo, 4.IV.1997) and the Council of Europe's Recommendation no. R (99) 4 of the Committee of Ministers to Member States on principles concerning the legal protection of incapable adults have been taken into account.

E. The scope of advance directives

WHAT SHOULD/SHOULD NOT BE COVERED IN AN ADVANCE DIRECTIVE

19. **Examples of areas covered by an advance directive.** Alzheimer Europe is in favour of advance directives being used to cover consent to treatment, refusal of treatment, resuscitation, palliative care, end-of-life care, requests concerning general care, decisions relating to residential and other types of care, financial decisions linked to the provision of care and statements about preferences (including psychological, spiritual and religious needs, relationships and lifestyle).

Although advance directives are usually not applicable to interventions on the body after death, making an advance directive is a good opportunity for a person to consider issues such as possible donation of organs and/or tissue for transplantation and/or research after death and to set out their views in writing.

20. **Terminology.** The terms "treatment", "care" and "health care" should be understood as referring to every aspect of treatment and care, not merely the medical aspects and not merely end-of-life treatment or care. For example, a person might wish to attend a day care centre, to have a bath instead of a shower, not to have breakfast, to go for a walk once a day etc. These kinds of wishes can also be included in an advance directive.
21. **Other uses for an advance directive.** We are also in favour of people using advance directives to indicate their wishes concerning the appointment of a health care proxy as well as their participation in research (please refer to the following two sections on health care proxies and research).

22. **Advance directives and place of treatment or care.** Advance directives should not be restricted to hospital care but should cover medical treatment irrespective of where it is provided e.g. at home, in nursing homes, in hospices etc.
23. **Proposed restrictions for the use of advance directives.** Alzheimer Europe is opposed to the use of advance directives for requests for clinically inappropriate health care or treatment, the refusal of basic care (washing and mouth care), the refusal of appropriate pain relief and the refusal of the offer of food and drink by mouth. It should, nevertheless, be possible to refuse artificial feeding, including gastrostomy, intravenous feeding and hydration and tube feeding, and to refuse over-sedation, or to tolerate some discomfort in order to be able to maintain awareness and/or retain some contact with family and friends.

HEALTH CARE PROXIES

24. **Appointment of health care proxies.** As stated above, it should be possible to use an advance directive to appoint a health care proxy with the power to make decisions on behalf of the person with dementia when the latter is no longer able to do so. Health care proxies are of two main types. Here we are referring to proxies appointed by the person with dementia while still mentally capable of doing so. Other terms in use include health care attorney and welfare attorney. Health care proxies may also be formal or court appointees, appointed when the person is no longer able to make competent decisions about his or her own health care, or appoint a proxy. Other terms include health care guardian or welfare guardian. In different legislations, there are various relationships between these proxy powers and others, such as those relating to financial affairs and property.
25. **Difference between health care proxy and legal guardian.** Health care proxies usually differ from legal guardians appointed to make financial or general decisions on behalf of a person as their powers are limited to health care decisions. In some countries, it is possible for a person to appoint a welfare attorney or guardian, who can also make health care decisions among others, or it may be possible to have a court appointed health care guardian.
26. **With or without written statement of wishes.** Alzheimer Europe supports the concept of health care proxies, either without any specific written guidance on the person's wishes or in combination with a written statement covering certain health care decisions.
27. **Advantage of having a health care proxy in addition to an advance directive.** We would encourage people making advance directives to consider the option of also appointing a proxy. Advance directives are often limited to specific circumstances or kinds of treatment. It can therefore be beneficial to have a health care proxy who has the power to make some or all decisions related to health care, particularly in situations not covered by the advance directive or in cases where the wishes contained in the advance directive are ambiguous or difficult to interpret e.g. due to recent medical advances or unforeseen health complications.
28. **Importance of discussing wishes with health care proxy.** A health care proxy should be aware of the preferences, values, beliefs and wishes of the person they are representing. For this reason, Alzheimer Europe, as well as being in favour of proxy measures in general, recognises the specific value of health care proxies in enhancing the autonomy of people with dementia in the domain of health care. We encourage people writing advance directives to discuss health care issues with the proxy decision maker and if appropriate to provide them with a statement of values (please see paragraphs 41 to 43 for details).
29. **Formalities linked to the appointment of health care proxy.** Details of the chosen health care proxy should be included in the advance directive e.g. name, address, phone number, email address etc. The health care proxy should have agreed to act as proxy and should sign the advance directive to show that they are in agreement and have read

the content. They should also receive a copy of it. The extent of the powers granted to the health care proxy should be recorded in the advance directive.

30. **Need for safeguards in legislation.** The concern that health care proxies might make decisions based on their own views, wishes or prejudices, as opposed to the prior wishes of the patient, should be covered by safeguards in legislation e.g. a complaints procedure or requirement to record decisions.

RESEARCH

31. **Advance directives covering participation in research.** Alzheimer Europe encourages the use of advance directives to cover wishes to participate in research (or not participate as the case may be). We feel that allowing consent in this way respects people's right to self-determination and their possible desire to do something constructive which may eventually benefit others with a similar medical condition.

32. **Safeguards for the use of advance directives for participation in research.** Whilst Alzheimer Europe accepts the provisions of the Convention on Human Rights and Biomedicine³ concerning therapeutic and non-therapeutic research in cases where a person with incapacity has not consented, we feel that consent to research in an advance directive should be accepted as a valid expression of a person's wish to participate in such research provided that:

- the person had the capacity to make such a decision (which may involve greater capacity than for other health care decisions);
- the person was willing to accept the kind of risks and/or burden involved. An indication should be given in the advance directive of the level of risk/burden that would be acceptable as the actual nature of the future research is unlikely to be known when consent is given in the advance directive;
- the person does not show any sign of unwillingness to participate at the start of the research e.g. refusing to take medication when offered, obvious distress when interviewed, etc.;
- the person is withdrawn from the research if they display signs of unwillingness to continue participating and/or experience distress as a result of the research;
- the research has been approved by an ethics committee with sufficient expertise in dementia issues. Alzheimer Europe strongly recommends that patient advocacy groups be consulted in this matter;
- the wellbeing of the research participants is appropriately monitored by an independent controller or control system;
- the health care proxy (if one has been appointed) is involved in determining whether the research that is eventually proposed is in line with the wishes expressed in the advance directive.

33. **Caution using "research advance directives" in residential/semi-residential settings.** Extreme caution should be exercised by researchers, ethics committees and external controllers in the case of people with dementia who consented in advance to

³ The Committee of Ministers adopted an Additional Protocol to the Convention on Human Rights and Biomedicine on Biomedical Research. It was opened for signature on 25 January 2005. Details of the Additional Protocol can be found at: www.coe.int/bioethics

Not all countries have ratified the Convention on Human Rights and Biomedicine.

participate in research and are currently living in an institutionalised or semi-institutionalised setting as they are in a situation of additional dependency on others (perhaps including those responsible for the research) which may affect their genuine willingness to participate. They may, for example, fear reprisals or want to avoid letting people down.

F. Practical issues linked to the writing and interpretation of advance directives

THE IMPORTANCE OF INVOLVING DOCTORS AND OTHER QUALIFIED HEALTH CARE PROFESSIONALS

34. **The role of doctors and other health care professionals.** Doctors and other health care professionals have an important role to play in informing patients about the possibility of making an advance directive and in explaining the nature and possible consequences of various treatment options. They can also serve as witnesses that the person producing the document has the necessary capacity to do so. However, some feel uneasy about approaching patients about advance directives, fearing that this might give a message that the patient's condition is hopeless or that the doctor is giving up on them. Doctors and qualified health care professionals should therefore be provided with guidance on how to deal with this issue.
35. **The use of vague or specific terminology.** When making an advance directive, it is important to pay attention to how it is worded, as this will effect its future interpretation. Whereas detailed and specific advance directives should leave medical staff in no doubt as to what a patient wants, such documents may actually be so specific that they are unlikely ever to fully correspond to a particular situation. On the other hand, documents containing vague terminology such as "heroic measures", "artificial means" or "terminal illness" may be difficult for doctors to interpret and could lead to a different interpretation to that intended. For these reasons, Alzheimer Europe feels that it is very important to discuss the content and terminology used in the advance directive with healthcare professionals.
36. **The necessity for and cost of consultation.** Adequate opportunity for discussion between patients and healthcare professionals may have to be built into the health care budget and doctors and qualified health care professionals should consequently be able to charge for this time. This cost should be borne by health insurances or whatever governmental funding arrangement pertains, and not directly by patients. Alzheimer Europe believes that writing an advance directive should be straightforward and a procedure which is free for patients.

THE FORM AND STYLE OF THE ADVANCE DIRECTIVE

37. **Writing an advance directive adapted to one's own needs.** Alzheimer Europe recognises that people have different reasons for making advance directives and that they come from different backgrounds (e.g. cultural, religious, educational etc.). Consequently, we are in favour of a flexible system which allows people to make advance directives that correspond to their particular needs and wishes. People should be permitted to draft their own advance directive, as available forms do not suit everybody's needs. Different examples exist on the Internet and are available from various organisations. However, as stated above, it would be wise to consult a doctor or other qualified health care professional when drafting an advance directive.
38. **Specific reference to dementia in the advance directive.** Alzheimer Europe favours the use of a form which specifically refers to dementia, as decisions concerning future care in the case of dementia are likely to differ from those made by people with other conditions. As dementia may exist alongside other medical conditions, it may be useful to choose a form which allows for treatment choices in relation to different scenarios e.g. dementia, dementia with terminal illness, dementia and coma etc.

39. **Focussing on quality of life or treatment options.** Alzheimer Europe accepts that some people might want to focus on outcomes (e.g. resulting quality of life, burden of the treatment, likelihood of a positive or negative prognosis) rather than on specific forms of treatment. This puts the onus on medical staff to decide which treatment corresponds best to the patient's wishes and to ensure that they have the necessary information, and have consulted with significant others⁴, to enable them to judge, if necessary, what constitutes quality of life for the person concerned. For this reason, we recommend that people who prefer to focus on outcomes consider the possible advantage of writing a "statement of values" (please see paragraphs 41 to 43 for details).
40. **Possibility of including a trial option.** Finally, we would like to draw attention to the possibility of including a trial option whereby a particular treatment is applied for a sufficient period of time to assess the benefit and burdens (or lack of them) of the treatment for the patient. This enables patients to benefit from potentially useful treatment without running the risk of the treatment being continued if it turns out to be futile, ineffective or unduly burdensome.

STATEMENT OF VALUES

41. **Advantage of writing a statement of values.** In view of the fact that it is difficult to ensure that an advance directive is sufficiently precise yet not too precise that it cannot be accurately interpreted in a given context, Alzheimer Europe encourages the use of "statements of values". A statement of values is a document which contains information about what is important and meaningful in life for the person writing it. It consists of a series of statements or answers to questions. Statements of values may help prevent third parties from making assumptions about a person's quality of life based on their own beliefs and values.
42. **How statements of values differ from advance directives.** Unlike advance directives, statements of values are not phrased in legal terminology and are not limited to medical treatment or care options. Statements of values are generally fairly lengthy and require detailed information. They provide valuable information about a person's background, beliefs, preferences and values which may facilitate the interpretation of advance directives, particularly in cases where the wishes stated do not fully correspond to the current situation. However, as they do tend to be very detailed documents and as preferences may change over the course of the disease, it is important to make sure that they are regularly updated for as long as this is possible.
43. **How statements of values can be used.** A statement of values, although generally clear in its intent, is not directive in terms of particular actions. For this reason, it may be beneficial given the uncertainties that often surround clinical decisions. We therefore recommend the use of statements of values as a supplement to advance directives or on their own.

REGISTRATION, USE AND REVIEW

44. **The need for a registration and retrieval system.** Whilst it is important that governments grant legal recognition of advance directives, their efficacy may be limited if there is no effective registration process and system of retrieval at the appropriate time. We as an organisation expect governments to set up registration procedures which fit in with their national procedures. Such procedures should guarantee confidentiality and not be excessively bureaucratic or over-formal. The registration of advance directives would contribute towards legitimising their use.
45. **Informing people about advance directives.** Governments should look into the possibility of setting up a system to routinely inform patients of their right to make an advance directive and a system of registration and retrieval in order to ensure that

⁴ For example relatives, a partner, a close friend, etc.

doctors are aware of the existence of a person's advance directive and have access to it when needed. However, it is important to bear in mind that people have different levels of education and financial resources. They may also be seriously ill and have restricted mobility. Consequently, the registration system should be simple, straightforward and cost-free for the person writing the advance directive. In some countries, it may be necessary to register the advance directive with a notary.

46. **Computerised recording.** The existence of an advance directive should be included in any computerised medical records (in accordance with the requirements of data protection laws). Alzheimer Europe would welcome cooperation between countries on this issue.
47. **Keeping and distributing copies of the advance directive.** Whether there is a registration procedure or not, a copy of the advance directive should be kept by the author for reference and stored in a place where it can be found when needed. A copy should also be given or made available to the doctor responsible for the person's care⁵ and to the specialist medical team if the person is receiving hospital care. The health care proxy or representative, if one has been appointed, and other people likely to be involved in future care should have a copy of the directive. It might also be helpful for people to carry a card (similar to donor cards) indicating that they have made an advance directive.
48. **Updating the advance directive.** As long as the author has the necessary capacity, the advance directive should be regularly updated (at least every 5 years). If no or minimal changes are decided, the document can be newly signed and dated. If a new document is required, older versions should be destroyed or marked as void and updated copies given to the relevant people. It should be borne in mind that the validity of older documents may in some cases be questioned due to recent medical advances.
49. **Withdrawal or amendment of the advance directive.** It should of course be possible to withdraw or amend an advance directive at any time provided that the person with dementia has the necessary capacity to do so. If a person has incapacity in many/most areas but firmly and clearly expresses a wish to revoke or amend an advance directive, doctors should assess that person's capacity as it specifically relates to the current issue and consider revoking or amending the advance directive. The overall process should be witnessed by an independent person and recorded in the person's medical file.
50. **Disposing of old copies of advance directives.** If an advance directive is withdrawn or amended, all copies of the former advance directive should be destroyed or marked as void.
51. **Witnesses and the certification of capacity.** The document may need to be witnessed in accordance with the usual legal practices, but in addition, there may need to be certification of capacity (if that is not assumed in law), by the doctor or another relevant professional.

In countries where witnesses are not legally required, the use of witnesses may help to strengthen the directive against future challenges to its validity. This may be particularly useful if the person making the directive is aware that significant others are likely to disagree with the wishes expressed within it.

⁵ By this term, we mean a doctor whom the patient would consult in the first instance for any medical problem. This doctor would then, if necessary, refer the patient to a specialist. Such doctors are called general practitioners in the United Kingdom. In certain other countries, they are called family doctors. In some countries, this concept does not exist as health care is organised differently.

CRITERIA FOR VALIDITY AND APPLICABILITY

52. **Validity criteria.** Alzheimer Europe is of the opinion that for an advance directive to be valid, certain criteria should be fulfilled.
- a) The person writing the advance directive must have the necessary and relevant capacity to do so. This means that the person should be capable of understanding the nature, purpose and likely consequences of possible treatment options to which they are consenting or refusing and the likely consequences of not receiving the treatment.
 - b) When writing the advance directive, the author should be free from undue influence or pressure from other people. The author of the advance directive should also bear in mind the possible effects of pain, depression, drugs or medication when choosing treatment options as these may influence any decisions made.
 - c) For an advance directive to be considered valid, it should be the most recent version made. Any wishes contained in an advance directive, which was made before the most recent version, should be considered invalid.
 - d) Wishes contained in an advance directive should be applicable to the circumstances and proposed treatment or care at the time the advance directive comes into force.
53. **Validity of advance directives in hospital and prison settings.** Advance directives, which fulfil the above criteria for validity, should be considered valid even if the author has been involuntarily placed in hospital or is serving a prison sentence. In the case of compulsory treatment orders, the advance directive should be advisory.
54. **Advance directives which do not correspond exactly to the current situation.** In the case of wishes which do not correspond exactly to the situation described in the advance directive, doctors should nevertheless act in the general spirit of the statement even though it may not be considered legally binding in the particular circumstances.
55. **Duration of validity of advance directives.** As dementia is a disease which can last for a number of years, during which time a person's mental capacity gradually declines, Alzheimer Europe is not in favour of setting a limit on the duration of validity of advance directives.
56. **Using existing documents as guidance.** A health care proxy must be guided by any currently valid advance directive or other advance statement in coming to the necessary treatment decisions.
57. **Importance of always trying to assess current views.** Doctors should only follow the instructions/wishes contained in an advance directive if the person who wrote it lacks the capacity to give or refuse consent to a particular treatment at the time the treatment is needed. The existence of an advance directive should not prevent doctors from trying to assess the current views of a person with dementia.
58. **Procedure in case of difficulty interpreting the advance directive.** Where advance directives are legally binding, doctors should be authorised to follow instructions or wishes contained in an advance directive without having to consult the health care proxy if there is no doubt about the meaning or validity of the document. In case of doubt about how to interpret the advance directive, the health care proxy, relatives and significant others, as well as the multi-disciplinary team, should be consulted.

ISSUES LINKED TO THE INTERPRETATION OF ADVANCE DIRECTIVES

59. **Discussion with others and avoidance of conflict.** When writing the advance directive, people should take their time and if possible discuss various issues with family/friends, and particularly those who are likely to be present when the advance directive is used. It would also be advisable to give a copy of the advance directive to family and close friends who could help ensure that it is kept up to date. This may reduce the likelihood of later conflict between family members/friends and/or medical

staff. It would also be beneficial for doctors to receive training in conflict management skills, and for relevant conflict resolutions procedures to be available.

60. **Discrepancy between past and present wishes.** Sometimes, there may seem to be a discrepancy between past and present wishes. For example, a person who consented to a certain form of treatment in advance may refuse it when the time comes or someone who gave an advance refusal of antibiotics may risk dying from an untreated condition even though they are showing clear signs of enjoying life and wanting to live. There is currently an ethical debate about the extent to which a person in an advanced stage of dementia is the same person (i.e. has the same personal identity) as the one who originally wrote the advance directive. Please refer to Alzheimer Europe's accompanying report for further details and a fuller discussion about this issue.
61. **Full personhood of people with dementia.** Whilst Alzheimer Europe encourages people to make their own minds up about such issues, we strongly object to any theory which calls into question the full personhood of people with dementia at any stage of the disease.
62. **Respecting current wishes.** Alzheimer Europe believes that if advance directives are to be taken seriously, the wishes contained in such documents should generally be respected. There are, however, two exceptions:
- Current competently expressed wishes cannot be overridden, and
 - Nobody should be subjected to medical treatment or suffer from a lack of medical treatment on the basis of a prior decision when it is obvious that they are currently displaying clear and unambiguous signs of wishes to the contrary.
- In such cases, staff should be able to act humanely in accordance with current professional standards and taking into consideration the context and the doctor-patient relationship and on the basis of good communication between all concerned, including the person with dementia. The advance directive should be regarded as part of this communication.
- Some may find the concepts of beneficence and non-maleficence of benefit or useful in this context.
63. **Responding to current wishes.** The degree to which any current ascertainable wishes and feelings should be respected will depend on a careful assessment of their competence and validity. Clearly, where they are judged to be fully competent and valid, any advance directive is not applicable. Even where they are relatively incoherent and deemed incompetent from a purely legal standpoint, they retain some validity as an expression of the person's current mental and emotional state and attitudes. In line with the principle of continuing personhood, these wishes and feelings should be considered alongside those expressed in the advance directive. The doctor in charge of treatment should consult with the health care proxy (if one has been appointed) and when necessary with significant others in order to determine the extent to which the current ascertained wishes and feelings of the person should modify or even override the treatment decisions which would have been made based solely on the advance directive. If there is disagreement between the doctor, the health care proxy and/or significant others as to whether the advance directive should be considered binding, or if the doctor and the significant others agree that the advance directive should be overridden, then the issue should be subject to some form of judicial or other independent review.
64. **When requests seem to contradict "best interests".** A problem may arise when requests made in an advance directive seem to go against what the doctor feels is best for the patient i.e. which would do them the most good and the least harm. Alzheimer Europe does not believe that doctors should ever be obliged or pressurised to act in a way that runs counter to their professional or personal beliefs and values.

65. **When the values or beliefs of doctors differ from those of patients.** On the other hand, the beliefs and values of individual doctors e.g. concerning life-prolonging treatment and the sanctity of life, should not be imposed on patients with different values and beliefs, or for whom they have no meaning.
66. **Training and counselling for doctors.** Alzheimer Europe recommends that doctors should receive training or counselling in questions related to advance directives such as their legal status, the consequences of respect and of non-respect, and ethical or personal dilemmas.

G. Legal issues

67. **Importance of advance directives recognised in Europe.** Although advance directives are not legally recognised in all countries in Europe, there are a few documents on a European level which refer to patients' rights to make advance decisions about health care issues and which may have been influential in guiding national laws in this domain.

68. **Governments urged to legally recognise advance directives.**

Alzheimer Europe urges governments to provide a clear statutory basis for effective advance directives with appropriate safeguards and a framework of procedures to ensure their effectiveness.

A growing number of its members consider that governments should legally recognise advance directives and make refusals of treatment expressed in advance directives legally binding albeit with adequate safeguards.

69. **Protection from criminal and civil liability when respecting advance directives.** If advance directives are to become legally binding and include wishes to forego life-saving treatment, life-sustaining treatment and the relentless pursuit of treatment which does not benefit the patient, as well as the administration of powerful or large doses of drugs to alleviate pain which may have the double effect of hastening death, doctors who comply with such advance directives in good faith should be protected from criminal and civil liability.
70. **Personal, moral or ethical reasons not to comply with an advance directive.** In non-emergency situations, doctors should be liable in civil or criminal law for failing to comply with a valid advance directive. If, for personal, moral or ethical reasons, the doctor does not comply, he/she should be obliged to transfer the care of the patient concerned to another doctor who is willing to comply with the advance directive. If this is not possible, the doctor should be obliged to obey the law and comply with a valid binding advance directive.
71. **Obligation to comply with advance directive in emergency situations.** If doctors have been informed of a patient's wishes through a valid advance directive prior to emergency treatment, they should of course be obliged to comply during emergency treatment. If, for personal, moral or ethical reasons, a doctor does not wish to comply with an advance directive and cannot, due to the urgent need for a decision regarding treatment, refer the patient to a colleague, he/she should be obliged to comply with a valid advance directive.
72. **Lack of awareness of the existence of an advance directive.** Doctors should not be liable in civil or criminal law for failing to comply with a valid advance directive if they are unaware of its existence and have no reason to suspect that one exists or cannot obtain a copy in time (e.g. in the case of emergency treatment).
73. **Procedure to follow in the case of non-respect of an advance directive.** Failure to respect wishes contained in an advance directive (whether or not it is legally binding), for example because it is not considered to be valid or to apply to the current

circumstances, should be documented in the patient's medical file along with an explanation for this failure. An explanation should also be provided to significant others and to any relevant supervisory body. Health care proxies should be informed of the reason so that they can challenge the decision, should they wish to do so.

74. **Intentional concealment or destruction of valid advance directive.** Anyone who intentionally conceals or destroys another person's currently valid advance directive (during that person's lifetime) should be guilty of an offence.
75. **The need for a specific reference in legislation to cover people with dementia.** Alzheimer Europe believes that existing legislation on advance directives which limits their validity to cases where a person is suffering from a terminal illness should be amended to specifically include people suffering from dementia who lack the capacity to make health care decisions, for example by including incurable and progressive conditions within the scope of the legislation.
76. **Legal recognition of health care proxy's right to make decisions.** We believe that decisions taken by a health care proxy, recognised by national law, should be respected, and that refusals of treatment by health care proxies should be legally binding except in exceptional circumstances. In such cases, the reason for failing to respect a proxy's decision should be documented and explained to the health care proxy and any relevant supervisory body.

H. End-of-life issues and the availability of palliative care

77. **Possible inequalities concerning access to treatment and care.** People do not all have the same level of access to medical treatment and palliative care e.g. due to insurance cover, marginalisation, availability of facilities/equipment or waiting lists. With regard to people with dementia and medical treatment/care, there is a risk that in the absence of formerly expressed wishes, their wellbeing may be further jeopardised by other considerations and factors.
78. **Limitations based on availability and appropriateness of treatment and care.** However, it must also be emphasised that a request for certain treatment or care cannot oblige doctors to provide it as they are limited to providing what is available and considered appropriate for the patient's medical condition in the light of current medical knowledge and practice.
79. **The risk of economic factors affecting end-of-life decisions.** For economic reasons and due to the lack of available palliative care in certain areas, some people may see the refusal of life-saving or life-sustaining treatment as the only option available to them. Alzheimer Europe believes that good quality palliative care should always be an option for people in the terminal stages of dementia.
80. **Ensuring that people with dementia are treated as valued and respected members of society.** When combined with constant messages about problems linked to the ageing population (particularly with regard to fears about insufficient funds to cover health care), some people may see options in advance directives to refuse life-sustaining and life-saving treatment as a message from society that some lives are less worthy of being saved or prolonged than others. Consequently, they may feel that it would be selfish to ask for all possible measures to be taken to prolong or save their own lives. Alzheimer Europe recognises its role in increasing awareness of dementia as a disease, reducing stigma attached to it, protecting the dignity of people with dementia of all ages and presenting a positive image of people with dementia within the wider community.
81. **Requests for palliative care may reveal inadequate provision.** In some countries, an increase in the number of people making specific requests regarding end-of-life

treatment is likely to reveal an inadequate provision of palliative care and consequently the necessity to improve the availability of such services and facilities.

82. **Steps must be taken to ensure that people with dementia have a real choice.** Alzheimer Europe urges governments to increase the availability and improve the quality of palliative care services/facilities in order to guarantee equity in the provision of health care and to ensure that people writing advance directives actually have a real choice.

I. Annex 1:

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J. Annex 2:

Alzheimer Europe and the working group would like to express their gratitude to the following people (in alphabetic order) who kindly gave their expert opinions about the draft version of this position paper. Their comments were taken into account and discussed by the Board of Alzheimer Europe and the working group. For this reason, the final version of the position paper does not necessarily reflect the exact views of each person:

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