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# *Alzheimer Europe Report*

The use of advance directives by people with dementia





# **Alzheimer Europe Report (1/2006)**



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Alzheimer Europe also gratefully acknowledges the generous support provided by Fondation Médéric Alzheimer to the Alzheimer Europe business plan programme on advance directives which allowed the organisation to carry out an extensive literature search and an overview of the legal situation of advance directives in Europe.

The position paper on advance directives represents the views of Alzheimer Europe alone and sponsorship of the organisation's business plan should not be construed as constituting an endorsement of the organisation's views on advance directives.



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*Preface*

## 1 Preface

In its business plan (2001-2006), Alzheimer Europe dedicated a programme to the promotion of the use of advance directives and other forms of advance statement for people with dementia and I had the honour of chairing the working group set up to develop a position of the organisation on this important issue.

I was delighted that the position developed by the working group was adopted unanimously at the Annual General Meeting of Alzheimer Europe in Killarney, Ireland on 9 June 2005 thus bringing our hard work to a successful conclusion.

Reaching consensus on such a difficult subject was no mean feat, if one considers that the member organisations of Alzheimer Europe represent significantly different legal and cultural traditions.

This publication presents the position that was adopted by Alzheimer Europe and its member organisations. At the same time, we felt that the literature search and the overview of legislation on advance directives, which were carried out by Alzheimer Europe, were equally deserving of being presented in this publication. These findings were instrumental in guiding us in the development of our position and will provide useful background information to any reader interested in advance decision-making in general and its particular relevance to people with dementia.

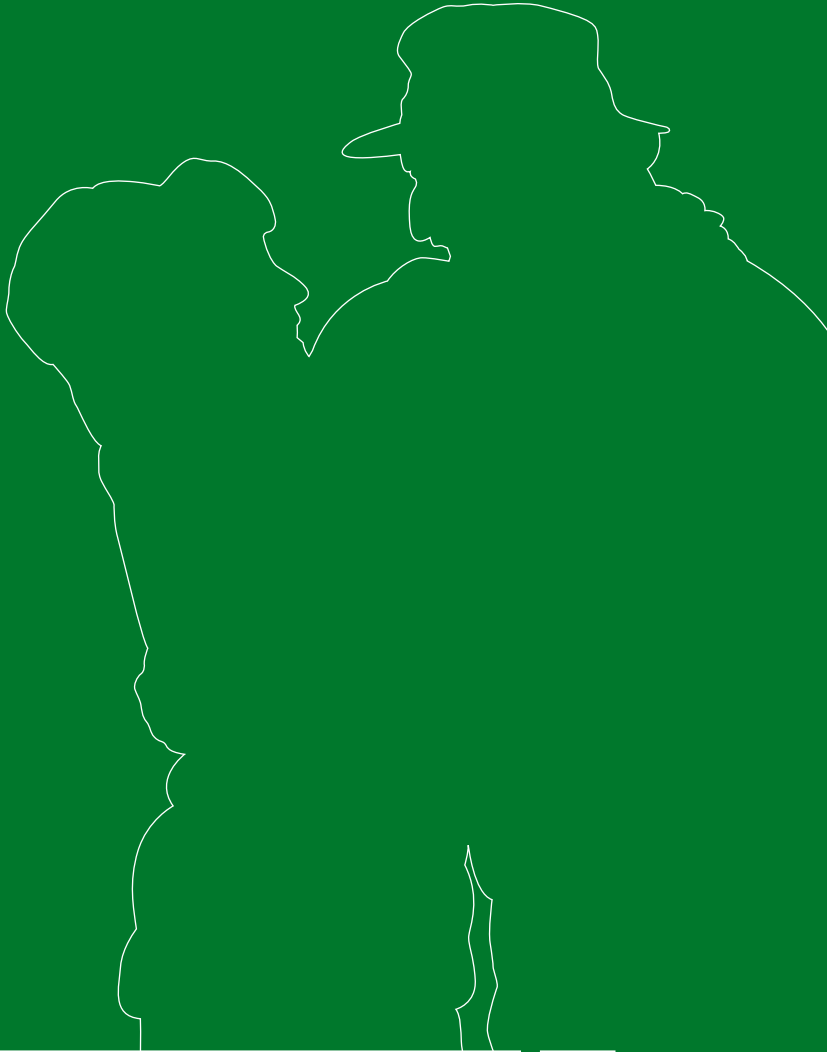
I am confident that this publication will be of great interest to people with dementia and their carers, but equally to policy makers and researchers who share the views of Alzheimer Europe on the importance of promoting the autonomy and dignity of people with dementia throughout the course of their disease, including at the end of their lives.

My heartfelt thanks go to Dianne Gove, the information officer of Alzheimer Europe and project manager for this programme. She carried out the extensive literature and legislation search, prepared various drafts of the different documents and successfully integrated the many comments of the members of our working group. I would of course also like to thank all of them (Peter Ashley, Holger Baumgartner, Dorthe Buss, Elaine Gadd, Jean Georges, Nicole Kerschen, Anna Mäki-Petäjä and Anna Rovira) for their active participation and useful contributions.

Finally, as with all projects of Alzheimer Europe, we would have been unable to carry out this work without the continued support of our corporate sponsors to all the activities set out in our business plan and we are particularly grateful to Fondation Médéric Alzheimer which provided specific support to this project on advance directives.

I hope that this publication makes a significant contribution to the discussions on how to involve people with dementia in decisions affecting their lives.

**Alan Jacques**  
**Honorary Secretary of Alzheimer Europe**  
**Chairperson of the working group on advance directives**



*Alzheimer Europe  
position on advance  
directives*



## 2 Alzheimer Europe position on advance directives

### 2.1 Executive summary

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.

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.

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.

- 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.
- 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.
- 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.
- 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.
- Alzheimer Europe expects governments to set up appropriate systems for the registration, use and review of advance directives.
- 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.
- 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.

- 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.
- 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.
- 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.

## 2.2 Introduction

### **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.

### **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.

### **Use of terms:**

- **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.
- **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:

- o **Instructions/requests** concerning medical treatment and/or health care;
  - o **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.
- **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.

### **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.

### **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;
- To set up a registration system.

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

### **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.

### **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.

## **2.3 Clarification on the use of advance directives in the case of dementia**

### **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 1960s<sup>1</sup>, 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.

### **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

<sup>1</sup> Maude, B. et al. (2004), Advance Medical Directives (living will, power of attorney and health care proxy) (Internet article: retrieved 31/3/2005 –

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.

#### **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.

#### **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.

## **2.4 Guiding principles**

#### **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.

- Every person diagnosed with dementia should have the right to be informed of the diagnosis as soon as possible. (§6)
- 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)

- 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)
- Alzheimer Europe has written an advance directive which is available in all the official languages of the European Union<sup>2</sup>. 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)
- 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)

### **General principles.**

The following general principles should also be borne in mind:

- 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.
- 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.
- 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

<sup>2</sup> 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.

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.

- 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.
- 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).

#### **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.

## **2.5 The scope of advance directives**

### **2.5.1 What should not be covered in an advance directive**

#### **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.

#### **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.

**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).

**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.

**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.

**2.5.2 Health care proxies****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.

**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.

**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.



**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.

**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).

**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.

**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.

**2.5.3 Research****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.

**Safeguards for the use of advance directives for participation in research.**

Whilst Alzheimer Europe accepts the provisions of the Convention on Human Rights and Biomedicine<sup>3</sup> 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:

<sup>3</sup> 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](http://www.coe.int/bioethics)

- 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.

**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 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.

## **2.6 Practical issues linked to the writing and interpretation of advance directives**

### **2.6.1 The importance of involving doctors and other qualified health care professionals**

**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.

**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 health care professionals.

**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.

**2.6.2 The form and style of the advance directive****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.

**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.

**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 others<sup>4</sup>, 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).

**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.

**2.6.3 Statement of values**

**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.

**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.

**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.

**2.6.4 Registration, use and review**

**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

<sup>4</sup> For example relatives, a partner, a close friend, etc.

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.

#### **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 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.

#### **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.

#### **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 care<sup>5</sup> 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.

#### **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.

#### **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

<sup>5</sup> 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.

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.

#### **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.

#### **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.

### **2.6.5 Criteria for validity and applicability**

#### **Validity criteria.**

Alzheimer Europe is of the opinion that for an advance directive to be valid, certain criteria should be fulfilled.

- 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.
- 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.
- 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.

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.

#### **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.

**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.

**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.

**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.

**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.

**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.

**2.6.6 Issues linked to the interpretation of advance directives****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.

**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.

### **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.

### **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;
- 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.

### **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.

**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.

**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.

**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.

**2.6.7 Legal issues**

**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.

**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.

**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.

**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.

**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.

**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).

**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.

**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.

**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.

### **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.

## **2.7 End-of-life issues and the availability of palliative care**

### **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.

### **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.

### **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.

### **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.

### **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.

**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.





*Advance directives –  
Findings of the Alzheimer  
Europe literature search*

## **3**     *Advance directives – Findings of the Alzheimer Europe literature search*

### **3.1**     **Introduction**

This report is intended to provide background information about some of the ethical, legal and medical debates surrounding the use of advance directives particularly with regard to people with dementia, which led to the writing of the Alzheimer Europe position paper on advance directives. When writing the position paper, we intended to look at the various issues involved from the standpoint of ideals (i.e. not concentrating solely on the current state of affairs) but also to take into account prevailing realities, potential conflicts and genuine limitations in order to stimulate further debate and hopefully work towards a resolution and change in the current situation. This report also contains a summary of some of the main advantages, disadvantages and criticisms to the use of advance directives. It does not necessarily reflect our views. These can be found in the position paper.

It is generally accepted that a competent and informed person has the moral and legal right to refuse unwanted medical treatment, including life-sustaining or life-saving treatment. It could be argued that, by definition, this right cannot practically be extended to people with dementia who, at the time of the proposed treatment, lack the necessary capacity to make decisions that are in their own best interests. However, it is widely agreed that it should be possible to extend this right into the future by means of an advance directive. People making advance directives may also appoint a health care proxy to take health care decisions on their behalf. Alzheimer Europe is in favour of promoting the use of advance directives amongst people with dementia and informing them about the possible advantages, limitations and drawbacks to their use.

### **3.2**     **Definitions and key concepts**

#### **3.2.1**     **What are advance directives?**

The story of Odysseus from Greek mythology illustrates well the idea of making decisions at one moment in time for some time in the future when one may be no longer capable of acting in one's own interests (Morgan, 2001). According to this story, Odysseus, who is navigating the rocks where Scylla and Charybdis reside, makes his sailors put wax in their ears and bind him to the mast of the ship in order to protect him from being lured to his death by the sirens. Although he later begs them to release him, the crew follow his previous orders and he is saved (Homer, 1991).

Sometimes the more general term “advance statement” is used to refer to a 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. It can be positive, negative or neutral. The term “advance statement” encompasses “advance directives”.

Advance directives are sometimes referred to as living wills. Although we feel that this term does not accurately describe the purpose and function of such documents, it is nevertheless a term which continues to be used in some countries, particularly those outside the UK, where there is currently only one term in use.

Advance directives relate to particular decisions or types of decision, 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. Negative advance directives typically cover two types of wishes:

1. Those which involve refusal of certain treatments (e.g. maintenance in a persistent vegetative state or resuscitation attempts) because the treatment or potential outcome is objectionable;
2. Those which cover the management of a deteriorating condition such as Alzheimer’s disease (e.g. non acceptance of antibiotics), whereby failure to treat may result in death even though the actual treatment is in itself not considered offensive or unpleasant (Morgan, 2001).

In some countries, the term “advance directive” 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. Advance directives can be used to provide guidance on and may alleviate some of the burdens of making difficult and sometimes contested quality of life decisions on behalf of incompetent patients (Robertson, 1991).

In this document, we will use the term advance statement or advance directive depending on the context. However, it is important to bear in mind that there is quite a varied use of the two terms by a variety of people in different contexts.

### **3.2.2 What are health care proxies?**

A health care proxy is a person who has been named by someone to make health care decisions on their behalf whenever they are unable to speak for themselves (e.g. due to incapacity) and/or communicate their wishes (e.g. due to being in a coma). As with advance directives, health care proxies are not limited to making decisions just at the end of a person’s life.

Some people provide the proxy with specific instructions about their preferences, others leave decisions entirely up to the proxy and some combine the two, leaving instructions about certain treatments or scenarios and not about others. Often the



person appointed is a member of the family or a friend. In some countries it is possible for a person to appoint a welfare attorney or guardian, who can make such proxy health care decisions, or it may be possible to have a court-appointed health care guardian.

Health care proxies have certain advantages over advance directives. For example, a health care proxy can generally make treatment decisions in a setting or in circumstances which were not previously considered by the person with incapacity, whereas an advance directive tends to be linked to specific named treatments or situations. In situations where it is unclear from an advance directive what the author actually wanted, a health care proxy may be asked to interpret the author's wishes as greater confidence is often placed in the judgment of a designated person than in a living will (Stein, 2003).

On the other hand, studies have shown that proxy decision makers do not always represent the wishes of the person with incapacity. People who appoint a health care proxy do not always inform them of their health care preferences. Proxies have their own preferences, priorities, values and beliefs which may come into play when they try to make decisions for the person with incapacity on the basis of best interests. They may also experience emotional conflict and pressure from family members. It is therefore not surprising that several studies have shown that proxies' and patients' decisions may differ (Reilly, 1994). It is therefore important that legal provisions include safeguards against eccentric or solipsistic decisions by health care proxies.

### **3.2.3 What advance directives do not generally cover**

Advance directives should not be confused with requests for active voluntary euthanasia, even though voluntary euthanasia societies have been active in pursuing this concept due to their humanitarian interest in the dying process. They should not be associated with the pro-death lobby as they may equally contain "pro-life" requests e.g. for life-prolonging or life-saving treatment. An advance directive may also contain details of the patient's wishes regarding palliative care. According to the Danish Council of Ethics (2003), a major difference between active euthanasia and the removal 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 as it no longer serves the purpose for which it was originally initiated i.e. to improve the patient's condition. Another possible justification for the removal of life-sustaining treatment is that the burden and risks that the treatment poses cannot be justified if the treatment is of no benefit.

Although decisions recorded in an advance directive may be closely related to treatment options towards the end of a person's life, an advance directive cannot in most jurisdictions be used to end a patient's life. There are, however, two exceptions to this. In the Netherlands, the "Termination of Life on Request and Suicide (Review Procedures) Act (2002)" contains provisions on advance directives relating to euthanasia. According to this act, an advance directive may be regarded as a request

for euthanasia by a patient who is unable to express his/her will. Doctors are not required to perform euthanasia but those who are willing to do so must (provided that it is lawful to perform euthanasia in each specific case) regard an advance directive as an expression of the will of the patient (Council of Europe, 2003). Nevertheless, Wortmann (2004) has suggested that an advance directive cannot be used to request active voluntary euthanasia in the case of patients with dementia as the request must have been expressed continuously and steadfastly by the patient over a long period of time. In Belgium, the Law on Euthanasia of 2002 permits a request made in an advance directive by a competent person to be respected provided that certain procedures are followed by the doctor and that a neutral third person (previously named by the author of the advance directive) is involved in interpreting the author's wishes (Hillebrand and Weiffen, 2002). Apart from these two exceptions, it must be borne in mind that advance directives are not generally linked to requests for voluntary active euthanasia in any way.

#### **3.2.4 The origins of advance directives**

The concept of a "living will" was first proposed by Luis Kutner in 1969 during a meeting of the Euthanasia Society of America. The idea behind the living will was that it would give people the opportunity to express the sentiment that when death is near and unavoidable, dignity and comfort should take precedence over feats to prolong life and postpone the moment of death, which are unlikely to add quality to the last days of life. The proposed living will was worded in rather emotive language:

"... death is as much a reality as birth, growth, maturity and old age – it is the only certainty in life. If the time comes when I, \_\_\_\_\_ can no longer take part in decisions for my own future, let this statement stand as an expression of my wishes, while I am still of sound mind. If the situation should arise in which there is no reasonable expectation of my recovery from physical or mental disability, I request that I be allowed to die and not be kept alive by artificial means or "heroic measures". I do not fear death itself, as much as the indignities of deterioration, dependence, and hopeless pain. I therefore ask that medication be mercifully administered to me to alleviate suffering even though this may hasten the moment of death."

#### **3.2.5 Palliative care and end-of-life care**

Many of the key issues surrounding the use of advance directives in the care of people suffering from dementia revolve around the right to refuse certain kinds of treatment (which may be considered necessary to prolong or save life) and to let symptoms run their natural course. As they near the end of their lives, people with dementia who expressed such a wish in an advance directive should be able to expect adequate care and consideration to relieve their physical and psychological suffering. The Finnish National Advisory Board on Health Care Ethics (ETENE) defines end-of-life care as follows:

“End-of-life care refers to the active care of a patient who is close to death, coupled with support for family and friends. It is treatment and support in the final stages of illness and during the process of death. A key aim of end-of-life treatment is based on the fact that the patient has a progressive, incurable illness for which prognosis-improving treatment is either not available or has been rejected by the patient, and that the patient’s life expectancy is considered to be short. End-of-life care as such is independent of the patient’s diagnosis.” (ETENE, 2003)

However, as dementia is in most cases an incurable disease which may last for several years, requests in an advance directive may cover issues relating to health care which do not concern life-saving or life-prolonging measures near the time of death but rather throughout the course of the disease. Advance directives could therefore contain requests or wishes for palliative care. Palliative care is a comprehensive approach to the care of people with incurable illnesses which considers death as a normal part of existence and therefore does not seek to prolong life at all costs. It is not limited to the last moments of a person’s life. ETENE describes some of the characteristics of palliative care as follows:

“Palliative care is not bound to the closeness of death and can last up to several years depending on the illness. Alleviating pain and other symptoms and addressing the psychological, social, spiritual and ideological issues are central to palliative care. The aim of palliative care is to ensure the well-being of the patient and his/her family and friends.” (ETENE, 2003)

### 3.2.6 Competence/legal capacity

Legal capacity concerns an individual’s capacity to make certain decisions and to perform certain acts. In all Member States of the European Union, an adult is presumed to have legal capacity unless proven otherwise. If a person lacks legal capacity (e.g. as a result of a disease, injury or developmental disorder), the State may deem him/her as incompetent and take the necessary steps to ensure that adequate protection is provided. In this way, capacity can be understood as a kind of threshold requirement for people to retain the power to make decisions for themselves.

However, it should be noted that there is not one capacity but several. Capacity is not an all or nothing affair, but should always be considered to be decision- or category-specific. There is no such thing as “general incapacity” but rather a wide range of potential “specific capacities” which refer to the ability to effectively carry out a variety of tasks e.g. driving a car, making a will, handling finances, consenting to medical treatment etc. The capacity to carry out such tasks is dependent on a person’s specific cognitive and physical abilities. A person might, for example, have the capacity to drive a car but not to manage his/her own financial affairs.

It is also possible to have limited capacity. This means that within a general or specific capacity, a person may have the capacity to perform some tasks but not others. For example, someone might be capable of writing cheques but not managing

more complex financial transactions, or they might be capable of driving in a familiar environment but not in an unknown town. Similarly, their competence might fluctuate throughout the course of the disease or even from one day or hour to the next.

Dementia is an organic brain disease which involves the gradual, progressive and irreversible (in the vast majority of cases) deterioration of a person's cognitive and physical capacity. In time, people with dementia gradually lose capacities and in many cases are eventually considered as legally incompetent in various areas of decision-making. As dementia progresses, numerous factors come into play which may affect peoples' capacity to consent<sup>6</sup> such as failing abilities, including impairment of perception, understanding, logical thinking, memory loss, poor motivation, dysphasia and dysgraphia; loss of the executive function of the brain, affecting standards, judgement, conscience, moral sense, planning, and causing an increased tendency to be influenced by others (which Scots law calls "facility"); and reactions to the experience of dementia, including denial, suspicion and paranoid ideas, dependence on others, anxiety and depression (Jacques, 2000). Balanced against this are the abilities that people possess and their continued interest and right to self-determination i.e. to make autonomous decisions about their own lives.

### **3.2.7 Assessing capacity**

According to Kennedy and Grubb (1994), whereas doctors ought to respect their patients' autonomy, they need only do so when a particular patient expressing his/her will is capable of behaving autonomously. Although the criteria for determining legal competence in the health care domain are generally laid down by law, doctors (including specialists and psychiatrists etc.) are responsible for the application of these criteria. It therefore follows that autonomy is a state of affairs granted by others – in the health care domain, by doctors.

In some countries, such as the UK, guidelines exist for doctors on the assessment of mental capacity e.g. the report of the British Medical Association and the Law Society (1995) entitled *Assessment of Mental Capacity – guidance for doctors and lawyers*. On a European level, it is interesting to note that neither the Biomedicine Convention nor the European Parliament and Council Directive on good clinical practice in the conduct of clinical trials on medicinal products on humans provide any guidelines on how competence should be assessed (Lötjönen, 2003).

There are, however, arguments both for and against regulation of the assessment of capacity:

“On the one hand, the power to evaluate an individual's competence and capacity to use his or her right to self-determination is perhaps one of the most far-reaching powers that can be given to a third party and should therefore be rigorously safeguarded from misuse and misinterpretation... On the other hand, picturing the various conditions that may compromise the ability in

<sup>6</sup> Please see section on consent.

individual decision-making and describing the methods of assessment to be used in each of the conditions would be a tremendous task for drafters of international legislation, not to speak of cultural differences that would have to be taken into account (Lötjönen, 2003, p367)."

Some representatives of the medical profession have in fact raised concern about this issue (Karlavish and Schmitt, 2000). According to Derouesné<sup>7</sup>, many doctors are ill prepared for such a task. Based on studies carried out in America involving geriatricians, neurologists and old age psychiatrists, he concludes that whereas there was general agreement about declaring "normal" subjects competent, this was certainly not the case for the evaluation of people with dementia. Another problem linked to the assessment of capacity of people with dementia, is that with some forms of dementia (e.g. Lewy Body Dementia), capacity may fluctuate considerably from one moment to the next. Consequently, competence must be assessed whenever a decision has to be made rather than once and for all.

### 3.3 Ethical issues

#### 3.3.1 The development of bioethics in Europe

The term "medical ethics" is often used to refer to the deontology of the medical profession covering issues such as moral rules, rules of etiquette and rules for professional conduct. The word "deontological" comes from the root "deon" which means duty or obligation in Latin.

The term "bioethics", on the other hand, was used for the first time by Potter, a biologist, in 1970 to refer to ethical problems linked to the present and the future of life in general and of human life in particular. Later, Helleger used the term to refer to a way to approach and resolve the moral conflicts raised by modern medicine (Gracia, 2001).

Bioethics is not just a series of principles but implies, in the European tradition at least, a moral obligation to act. Kant, a German philosopher from the Enlightenment period, was concerned with the motivation behind any action. He stated that action done from duty has its moral worth not in the purpose to be attained by it but in the maxim in accordance with which it is decided upon. He developed the Categorical Imperative which states, "Act only on that maxim whereby you can at the same time will that it should become a universal law or a universal law of nature" (In Kuczewski, 2004).

In Europe, bioethics is very much based on the principle of solidarity, as well as freedom, tolerance, equal opportunity, social justice and human dignity. The gradual and continued expansion of the European Union has led to new possibilities and potential problems in the health care domain. At the same time, efforts are constantly underway to harmonise health care provision, promote co-operation and find consensus on a variety of healthcare issues. In 1992, the Maastricht Treaty on the European Union made public health an object of EU policy (Ten Have, 2001).

<sup>7</sup> Unpublished report.

However, long before this, the Council of Europe had decided to set up a single specialised committee to deal with bioethical issues. This committee, the Steering Committee on Bioethics, was granted permanent status in 1992. This came just one year after the Commission of the European Union set up the Group of Advisers on the Ethical Implications of Biotechnology (GAEIB).

In 1997, the Council of Europe's Convention on Human Rights and Biomedicine was signed by 21 member states in Oviedo, Spain. Its emphasis on the principles of human dignity and solidarity can be clearly detected in some of the recitals of the preamble:

- Convinced of the need to respect the human being both as an individual and as a member of the human species and recognising the importance of ensuring the dignity of the human being;
- Conscious that the misuse of biology and medicine may lead to acts endangering human dignity;
- Affirming that progress in biology and medicine should be used for the benefit of present and future generations;
- Stressing the need for international co-operation so that all humanity may enjoy the benefits of biology and medicine;
- Wishing to remind all members of society of their rights and responsibilities.

### **3.3.2 The American influence**

In the United States, the Belmont Report of 1978 on ethical principles and guidelines for the protection of human subjects of research was influential in defining bioethics. The report came in response to public concern over the Tuskegee study which ran from 1932 to 1972. The study involved over 400 poor African-American men who were denied treatment in order to monitor the natural course of a disease. The Belmont Report outlined 3 principles – respect for persons (i.e. autonomy), beneficence and justice. In 1983, Beauchamp and Childress published a text book on the principles of biomedical ethics in which they adopted the three principles of the Belmont Report and added a fourth principle, that of non-maleficence. Some of these principles, which are discussed in the next subsection, can be traced back to the Hippocratic tradition, which in turn is reflected in many European codes of deontology. They are also reflected in the Council of Europe's Convention on Human Rights and Biomedicine.

Nevertheless, some authors have criticised the American approach for placing too much emphasis on individual rights:

“European authors tend to emphasize the social and cultural context of many ethical debates. They are focusing attention on the structure and organisation of the health care system, as well as the network of social values in which the

moral problems are presented. They criticize the individualistic focus of dominant bioethical discourses and the relative negligence of community values, interpersonal relationships and solidarity. Individualistic ethics in their view should be complemented with social ethics” (Ten Have, 2001, p. 8).

### 3.3.3 Four common bioethical principles

#### 3.3.3.1 *Respect for autonomy*

One of the most widely used frameworks for considering bioethical issues is that provided by Beauchamp and Childress (1994), which outlines 4 main principles: respect for autonomy, beneficence, non-maleficence and justice.

The word *autonomy* comes from the Greek *autos-nomos* meaning “self-rule” or “self-determination”. According to Kantian ethics, autonomy is based on the human capacity to direct one’s life according to rational principles. He states,

“Everything in nature works in accordance with laws. Only a rational being has the capacity to act in accordance with the representation of laws, that is, in accordance with principles, or has a will. Since reason is required for the derivation of actions from laws, the will is nothing other than practical reason” (In Korsgaard, 2004).

Rationality, in Kant’s view, is the means to autonomy. Autonomous people are considered as being ends in themselves in that they have the capacity to determine their own destiny, and as such must be respected.

For John Stuart Mill, the concept of respect for autonomy involves the capacity to think, decide and act on the basis of such thought and decision freely and independently. Mill advocated the principle of autonomy (or the principle of liberty as he called it) provided that it did not cause harm to others:

“That the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant. ... Over himself, over his own body and mind, the individual is sovereign” (Mill, 1968, p. 73).

The principle of not causing harm to others (known as Mill’s “harm principle”) provides the grounds for the moral right of a patient to refuse medical treatment and for a doctor to refrain from intervening against the patient’s wishes. Nevertheless, Mill believed that it was acceptable to prevent people from harming themselves provided that their action was not fully informed.

Nowadays, an autonomous decision might be described as one that is made freely/without undue influence, by a competent person, in full knowledge and understanding of the relevant information necessary to make such a decision. It should also be applicable to the current situation or circumstances.

Many people see dementia as a humiliating disease involving a deterioration of mental power, the loss of one's former personality and identity and eventually becoming a burden to others. Many dread the prospect of being deprived of the chance to decide their own fate and thus exercise their right to self-determination. Fears linked to this perception of dementia may include the fear of under-treatment (on the grounds that dementia cannot be cured) and the fear of over-treatment, thereby prolonging the suffering that accompanies dementia (Hertogh and Ribbe, 1996).

Self-determination is a central principle in health care, which is gradually moving away from a paternalistic approach towards a more individualistic, client-centred approach where the patient plays a more active role in his/her own health and well-being. Such an approach requires that patients take responsibility for making their own decisions and also that they bear the consequences of those choices.

However, it should be borne in mind that not everyone agrees with the emphasis that is currently placed on autonomy. For example, although the Danish Council of Ethics (2003) appreciates individuals taking responsibility for their own lives, it points out that the ideal of personal autonomy is based on extreme individualism and that this viewpoint takes the focus away from the fact that people are always influenced and to some extent dependent on others. They are what they are as a result of interactions with others and a particular history. Similarly, the Finnish National Advisory Board on Health Care Ethics - ETENE - (2001) cautions against concentrating almost exclusively on the principles of autonomy and self-determination. Whilst these principles may serve to protect patients from abuse and give them an active role in their treatment, ETENE states,

“...it is important to understand that help for a human being cannot be based on just a single, isolated principle – and far less on its mechanical application. Alongside self-determination, the principles of the common good, community and equity, among others, demand to be taken just as seriously.”

Nevertheless, the possibility to exercise some degree of autonomy, through advance consent or refusal of medical treatment and/or care, could be beneficial to many people with dementia.

### **3.3.3.2 *Beneficence and non-maleficence***

Beneficence involves balancing the benefits of treatment against the risks and costs involved, whereas non-maleficence means avoiding the causation of harm. As many treatments involve some degree of harm, the principle of non-maleficence would imply that the harm should not be disproportionate to the benefit of the treatment. Respecting the principles of beneficence and non-maleficence may in certain circumstances mean failing to respect a person's autonomy i.e. respecting their views about a particular treatment. For example, it may be necessary to provide treatment that is not desired in order to prevent the development of a future, more serious health problem. The treatment might be unpleasant, uncomfortable



or even painful but this might involve less harm to the patient than would occur, were they not to have it.

In cases where the patient lacks legal competence to make a decision, medical staff are expected to act in the best interests of the patient. In doing so, they may take into account the principles of beneficence and non-maleficence. However, it would be helpful for medical staff in such cases, if the patient lacking capacity had made an advance directive. Nevertheless, as will be seen in the following section on “the position of advance directives alongside current wishes”, problems may arise when there is a conflict between what a person requested in an advance directive and what in the doctor’s view is in their best interests, particularly in cases where it is no longer clear that the person in question would still agree with the decision previously made.

In Western medicine, the principles of beneficence and non-maleficence derive historically from the doctor-patient relationship, which for centuries was based on paternalism. In the last few decades, there has been a change in the doctor-patient relationship involving a move towards greater respect for patients’ autonomy, in that patients play a more active role in making decisions about their own treatment (Mallia, 2003). According to Kao (2002), this is not the same in non-Western medicine. She explains that in Islamic medical ethics, a greater emphasis is placed on beneficence than on autonomy especially at the time of death. Aksoy and Tenik (2002), who investigated the existence of the four principles in the Islamic tradition by examining the works of Mawlana, a prominent Sufi theologian and philosopher, support this claim. They found evidence of all four principles in one form or another, with a clear emphasis on the principle of beneficence. In China where medical ethics were greatly influenced by Confucianism, there is also a great emphasis on beneficence in that Chinese medicine is considered “a humane art, and a physician must be loving in order to treat the sick and heal the injured” (Kao, 2002).

### **3.3.3.3 Justice/equity**

The principle of “justice/equity” could be described as the moral obligation to act on the basis of fair adjudication between competing claims. As such, it is linked to fairness, entitlement and equality. In health care ethics, this can be subdivided into three categories: fair distribution of scarce resources (distributive justice), respect for people’s rights (rights-based justice) and respect for morally acceptable laws (legal justice) (Gillon, 1994).

The right to be treated equally, and in some cases equal access to treatment, can be found in many constitutions, but in actual practice, a number of different factors may influence actual access to treatment e.g. age, place of residence, social status, ethnic background, culture, sexual preferences, disability, legal capacity, hospital budgets, insurance cover and prognosis. This could equally apply to equality in the provision of care in the sense that certain people or groups of people might not be treated with the same degree of respect e.g. with indifference, unfriendliness, lack of concern or rudeness.

Gillon (1994) emphasises that justice is more than mere equality in that people can be treated unjustly even if they are treated equally. With reference to Aristotle, he argues that it is important to treat equals equally and unequals unequally in proportion to the morally relevant inequalities (the criterion for which is still being debated). Situations will always arise where decisions have to be taken and there are limited resources, different options and/or other conflicting moral concerns. Care must be taken to ensure that health care resources are used sensibly and fairly. People with dementia are potentially vulnerable in that they are likely at some stage to be unable to state their preferences and ensure that they are respected. Advance directives at least provide written evidence of their wishes, which should go some way towards ensuring that they are not placed at a disadvantage to others when it comes to making crucial decisions about their health and well-being. Health care proxies could also play a useful role in making sure that such decisions are taken into account and as far as possible respected.

### **3.3.4 Advance directives and current wishes**

#### **3.3.4.1 *The current debate***

Clear and unambiguous wishes expressed in an advance directive may help doctors to decide on a course of treatment or care. However, a problem arises when alongside a valid advance directive, a patient has current wishes (regarding proposed treatment for which he/she does not have decision-making capacity) which may be more or less clearly expressed, more or less consistent and more or less in agreement with the view expressed in the advance directive. This can create a dilemma for doctors who are then put in the position of having to choose between formerly and currently expressed wishes. Opinions differ on this issue. Some people believe that an advance directive should be strictly followed irrespective of current wishes, whereas others take the stance that it should only be followed in the absence of clearly expressed current wishes. Other opinions tend to fall between these two extremes. Below, you will find a summary of some of the philosophical/ethical arguments linked to this issue.

#### **3.3.4.2 *Dworkin – the importance of critical interests***

In “Life’s Dominion: An argument about abortion, euthanasia and individual freedom”, Dworkin (1994) considers the right of people lacking capacity to autonomy. He acknowledges that competent individuals have the right to make decisions which might not necessarily seem logical, wise or in their best interests but that adults with incapacity do not have this same right. Dworkin puts forward the *evidentiary* view as a possible explanation, which basically supposes that people do in fact know what is in their best interests, and that consequently, other people should not interfere. In the case of people with incapacity, it would be presumed that they do not know what is in their best interests but that other people, for example specialists like doctors, do. However, he acknowledges that this is clearly not the case, as competent adults regularly and freely make decisions in full knowledge that they are not in their best interests e.g. continuing to smoke despite repeated health warnings about the dangers.

With regard to advance statements, Dworkin points out, “People are not the best judges of what their own best interests would be under circumstances they have never encountered and in which their preferences and desires may drastically have changed” (p.226). Another theory of autonomy is therefore needed to justify respecting wishes contained in an advance directive.

Dworkin proposes the *integrity* view of autonomy. This approach considers autonomy as a reflection of a person’s integrity as opposed to being based on concerns for their welfare. Taking the previous example of smoking, an autonomous adult may be fully aware that it is not in their best medical interests to smoke but may feel that the personal benefit they gain from smoking outweighs any possible negative effects on their health. In this sense, it derives from the capacity to express one’s character through the life that one leads – based on values, commitments, convictions and critical as well as experiential interests:

*Experiential interests:* The things that people do just because they like the experience of doing them e.g. cooking or eating out, going out with friends, doing sport, going to the cinema etc. The value of such things depends on the fact that people find them pleasurable or exciting as experiences. It is not important if other people like them and their lives are unlikely to be any less valid for not liking them. Other experiences are often avoided as they are painful or unpleasant but if another person enjoys them or doesn’t mind them (e.g. going to the dentist’s), it is generally no problem.

*Critical interests:* Interests, which if not satisfied, people would think they were worse off in some way or that their life had been wasted. These are convictions about what helps to make a life good on the whole. They represent critical judgments rather than experiential preferences. They are the kind of things that make a person think, had it not been so, their life would have been worse or wasted e.g. having a close relationship, accomplishing a particular task or fulfilling a duty.

Such a theory of autonomy should recognise the right to make choices that seem irrational or may be based on weakness, indecision or caprice. It supports people’s right to lead their lives as they see fit based on what is important to them provided that their lives reflect a general, overall integrity and authenticity.

According to Dworkin, “if his (the person with dementia) choices and demands, no matter how firmly expressed, systematically or randomly contradict one another, reflecting no coherent sense of self and no discernable even short-term aims, then he has presumably lost the capacity that it is the point of autonomy to protect”. Dworkin goes on to suggest that in such cases, people only have the right to beneficence (the right that decisions be made in his/her best interests) but that their preferences may, for different reasons, be important in deciding what their best interests are.

Clearly, conflict may arise when doctors try to balance respect for the principle of beneficence with respect for a person's right to autonomy. One might ask whether the former can be considered as a reason to ignore a person's precedent autonomy. In other words, if a person seems to be enjoying life in some way, would it be justifiable to withhold life-supporting treatment on the basis of a previously made request? Maintaining life-supporting treatment would violate rather than respect their autonomy.

Dworkin claims that people with dementia in the later stages have no sense of a whole life with a past joined to a future and that they cannot have the projects or plans of the kind that leading a critical life requires. Furthermore, they are no longer able to act in a way that would make life more or less valuable. Consequently, although there may be a conflict between a person's precedent autonomy and contemporary experiential interests (if they are clearly enjoying life or some aspect of it), there is no conflict with their critical interests as they perceived them whilst still competent.

Dworkin gives the example of a woman who asked not to be given medical care for life-threatening illnesses contracted after she had acquired dementia. Dworkin states that neither her right to autonomy nor her right to beneficence would give grounds for denying that request, even if she seemed to be enjoying life, as it would constitute a lack of compassion "toward the whole person, the person who tragically became demented". He points out that even though experiential interests seem to take precedence over critical interests in advanced dementia, it is no reason to ignore the critical interests they had when competent.

Dworkin's view of a person with dementia seems to be one in which the person at a particular stage of their life has dementia, but this is just one stage in their complete life which has already involved different stages. As such, the stage they are now in, is affected by interests and concerns which transcend that stage and are important for their life as a whole. As such, the competent and incompetent selves are one and the same person. The critical interests, which previously gave meaning and coherence to life, are still important, even if at this particular moment in time, the experiential interests seem to be more in the foreground. Dworkin's account would seem to suggest that advance directives should be respected because they are to be viewed as expressions of the critical interests a person has, which are relevant to their whole life and which should take precedence over current experiential interests. Failure to respect them would, in his view, constitute "an unacceptable form of moral paternalism".

### ***3.3.4.3 Derek Parfit – the psychological view of personal identity***

Parfit takes the view that personal identity is constituted over time by varying degrees of continuity between former and later selves in terms of a wide range of psychological and physical features. The psychological aspect of personal identity is constituted by the degrees of similarity between two temporally separate selves

with regard to a person's personality, belief structure and desires, which may in certain cases (such as advanced dementia) depending on the degree of similarity and continuity, move from being intra-personal to being inter-personal.

In certain cases of advanced dementia, it could be argued that psychological continuity is so deeply disturbed that someone has become another person. In such cases, an advance directive should have no more moral force in connection to the course of action to be currently taken than it would have had, had it been written by a stranger, friend or relative. A person with advanced dementia may have totally different interests to those they had as a person without dementia. It would follow from Parfit's theory, that there are no moral grounds to respect advance directives in such severe cases.

However, according to Parfit, continuity between the former and current self is a matter of degree in that there may be a strong, weak or no relationship at all between the different selves. With reference to advance directives for research involving people with dementia, Berghmans (1998) states that according to the psychological view of personal identity, the moral authority of an advance directive would be less diminished in the earlier stage of dementia than in the later and more severe stages because memory loss and other psychological changes would not be as marked as in the later stages. This observation could presumably be applied to advance directives involving wishes other than those linked to participation in research.

#### **3.3.4.4 Dresser – respecting a person's current subjective experience**

Dresser (1995) agrees with Parfit in the sense that the person with dementia could be considered as a different person to their former self and that in such cases, one might ask why the wishes of the former self (someone else) should take precedence over those of the current self.

Dresser takes the stance that a care and treatment policy should be centered on the conscious incompetent patient's subjective reality. She does not seem to be against respecting a wish which could lead to death provided that the experiential burden of continued life seems to be too heavy or the benefits too minimum but that when a person's subjective experience seems positive, attempts should be made to delay death. Such an approach is clearly dependent on the ability to accurately assess the experiential benefits and burdens of people in the advance stages of dementia, which incidentally Dresser thinks possible. She concludes, "Their loss of higher-level intellectual capacities ought not to exclude people ... from the law's protective reach, even when the threats to their well-being emanate from their own former preferences." She summarises Dworkin's approach as "an elegant theory that may lead to a questionable policy".

Nevertheless, such an approach might not be possible in all countries. In Germany, for example, two of the three propositions laid down in the Principles of the Ger-

man Medical Association concerning terminal care (1998), are the refusal of any medical assessment of the value of life or the quality of life by doctors and the respect for patients' wishes, including those made in an advance declaration (in Wegener, 2000)

#### **3.3.4.5 Robertson - discontinuity of interests**

Robertson is another theorist who recognises the possibility that the value-based interests of a competent individual may be radically different from the simpler, experiential interests of an individual with severe incapacity. He states:

“The values and interests of the competent person no longer are relevant to someone who has lost the rational structure on which those values and interests rested. Unless we are to view competently held values and interests as extending even into situations in which, because of incompetency, they can no longer have meaning, it matters not that as a competent person the individual would not wish to be maintained in a debilitated or disabled state. If the person is no longer competent enough to appreciate the degree of divergence from her previous activity that produced the choice against treatment, the prior directive does not represent her current interest merely because a competent directive was issued” (Robertson, 1999).

Whilst Robertson accepts that competent people may well have an interest in controlling their future, he is doubtful as to whether the advance decisions they take will necessarily reflect the best interests of their future self. He states that there may be a conflict between the interests of the past competent self and those of current incompetent self and that in such cases, there is a risk that the wishes of the competent self may be privileged. For this reason, he believes that advance directives may pose a threat to people with incapacity and consequently should not always be respected, particularly in cases where the patient clearly “has an interest in further life”.

#### **3.3.4.6 Buchanan - psychological continuity and personhood**

According to Buchanan (1988), as long as strong connections exist between the person who wrote the advance directive and the current self, advance directives should be used. However, there may come a time when the person has lost not only connections or similarities with their former self, but no longer has any kind of continuity with people in general. Buchanan uses the term “non-person” to describe people who in his eyes have reached this stage. Of course, one could argue that there is more to personal identity than psychological continuity. Moreover, one cannot claim with any degree of certainty that a person with dementia even in the latest stages is unable to experience any psychological states. As pointed out by Kuhse, people with severe dementia are capable of experiencing states of consciousness and have interests.

Buchanan criticises the psychological view of personal identity stating that “the very process that renders the individual incompetent and brings the advance

directive into play can – and indeed does – destroy the conditions necessary for his or her personal identity and thereby undercut entirely the moral authority of the directive.” In his view, the advance directive serves to protect the interests of the author of the advance directive, which have much greater moral weight than the experiential interests of the “non-person that succeeds” them.

#### **3.3.4.7 Kuhse – existence over time**

Whilst Kuhse (1999) accepts the argument by Robertson and Dresser that advance directives are conceptually confused because they rely on inapplicable notions of self-determination and personal identity, she believes that this does not justify overriding refusals of life-sustaining treatment.

Kuhse agrees with Buchanan who describes people suffering from advanced Alzheimer’s disease as having only very truncated interests and mental capacities that “are much less sophisticated than those of a small child or nonhuman animal such as a dog”. She adds that people with severe dementia lack the capacity for self-consciousness, rationality and purposive agency, and have no conception of themselves existing over time, even though they are capable of experiencing pain and pleasure - basically, they lack a vision of their lives as extending into the future. She quotes Tooley (1983) who argues that the ability to see oneself as existing over time is a necessary condition for being a person and for having a “right to life”.

On the basis of this argument, Kuhse concludes “it would thus not be directly wrong to allow a human individual who is not a person to die painlessly [...] and to argue that the advance refusal of life-sustaining treatment by a person should be honored if the individual that succeeds her is not a person, that is, does not have an interest in her own continued existence.”

Kuhse acknowledges that even in the most advanced stage of dementia, people have an interest in avoiding pain and discomfort and therefore does not condone withholding pain and symptom relief even if the person refused this in advance of receiving palliative care to alleviate pain and suffering.

#### **3.3.4.8 Key considerations on personal identity and advance directives**

Two key questions with regard to personal identity and advance directives are:

- Is the person who writes an advance directive necessarily the same person as the one to whom it will apply later (in the case of advanced dementia)?
- Should previously expressed wishes (i.e. in an advance directive) take precedence over currently expressed wishes (by a person with incapacity)?

Clearly, advance directives may be made by people from all walks of life, who would perhaps give very different answers to these questions. Lay people’s views about personhood differ. Sapp (1998), for example, argues that if a person:

“...Were to retain bodily integrity and vitality but to lose consciousness, rationality and the capacity to make autonomous choices, most people would simply take the commonsense position that of course this is still a human being even if some or even most of these capacities have been lost.”

Luis Bunuel, the filmmaker, on the other hand, is quoted as having said,

“You have to begin to lose your memory, if only in bits and pieces, to realize that memory is what makes our lives. Life without memory is no life at all.... Our memory is our coherence, our reason, our feeling, even our action. Without it, we are nothing” (Sacks, 1986, p.34).

Whilst Alzheimer Europe does not take a stance on the first question, it does object to any attempt to classify people with dementia at any stage of the disease as anything other than full human beings entitled to the same amount of consideration and respect as any other group of people. Post describes personhood as being more complex than just a baseline of self-awareness and cognition - a claim which would surely be backed up by authors such as Killick, Barnett, Ignatieff and Goldsmith who all indicate that even people with severe dementia have awareness and a voice which can be heard if one listens to it (Cox, 2003). In any case, irrespective of whether one accepts that the person with advanced dementia is the same person as the author of the advance directive, we can see no justification for showing any less respect to any person on the grounds that they are suffering from severe incapacitation or cognitive damage.

Nys (1997) points out that from a legal point of view what is important is that the person who writes an advance directive has reflected on the issue of continuity or discontinuity. This would imply that they were aware of how the disease might progress and what the consequences might be on their awareness and personal identity.

Regarding the second question, if advance directives are to be taken seriously and serve as a means to exercise one's autonomy at a time in the future when it would otherwise be no longer possible, then people should be able to count on their wishes being respected. People should be aware when writing them that they may change in the course of the disease so that they are sure that they really want to make binding decisions and/or whether they wouldn't prefer to appoint a proxy. Ideally, having considered this issue, a person could record in the advance directive what should be done in case of conflict between past competent wishes and current incompetent wishes e.g. to respect the advance directive, ask for the opinion of a medical expert or speak to the proxy etc.

In the absence of such a statement, we do not consider that any person should be subjected to medical treatment or suffer from a lack of medical treatment on the basis of a prior decision when it is clear that they are currently displaying clear signs of wishes to the contrary. In such cases, medical staff should be able to act humanely and according to the principles of beneficence and non-maleficence.



## 3.4 Research issues

### 3.4.1 Advance directives and non-therapeutic research

There is a scientific need to conduct research into dementia for which it is necessary to involve people with dementia who are in the later and more advanced stages of the disease process. As this is also the stage when it is not possible to obtain their consent scientists and researchers are faced with a huge problem. There is a need to balance the protection of vulnerable adults with their right to choose to participate in such research should they wish to do so. According to High et al. (1994), “To deny persons access to research participation out of fear of exploitation of specific groups of persons is to avoid rather than accept and practice ethical responsibility”. Lötjönen (2003) describes the dilemma that the safety and likely benefit of some research might only be proved by carrying out research on incapacitated adults as a deadlock. She says that this explains why research on such people has become an issue of controversy from both an ethical and legal perspective.

One solution would be to encourage people in the early stages of dementia to consider this issue and record their wishes in an advance directive. The use of advance directives for research could serve three purposes: 1. to enable people with dementia to do something constructive which may eventually benefit others in a similar situation, 2. to protect vulnerable individuals from being exploited by scientists and researchers, and 3. to promote scientific progress by enabling scientists and researchers to conduct research involving people with dementia which may eventually entail preventative, diagnostic and therapeutic benefits. Of course, an advance directive could equally be used to record a person’s refusal to take part in research.

### 3.4.2 Advance directives and legislation

Legislation relating to consent to treatment does not generally cover consent to participation in research. This may be due to the fact that research is not carried out to improve a particular person’s health. For example, a person with dementia who takes part in a clinical trial for a new drug may be given a placebo rather than the actual drug and even those who receive the drug that is being tested are not guaranteed to benefit from it in any way. That is one of the reasons it is being tested. They may even suffer from minor or major side effects. Whether or not the research is likely to benefit the person with dementia participating in the research, that person may be exposed to a certain degree of discomfort, inconvenience and/or risk. These are important issues to bear in mind when considering whether or not to participate in research.

The Georgian Law on Health Care of 1997 contains a provision relating to the participation of adults with incapacity in educational or scientific research. Article 11 of this law states that a medical intervention or involvement in educational or scientific research of a person who is unable to consent is only admissible if their previously expressed will is taken into consideration (expressed when they were able to consent). In the absence of this, consent must be given by the patient’s relatives and/or legal representative.

The Mental Capacity Act of 2005 (applicable in England and Wales) contains a section on research in which it is stated that a person who is unable to consent may participate in research projects provided that certain conditions are fulfilled. One condition is that the researcher identifies a carer (or another person interested in the person's welfare) who can advise as to whether the person with incapacity should take part in the research and what the wishes and feelings of the person with incapacity about participation would be likely to be if they had the necessary capacity to decide. Elsewhere in the Act, it is stated that in determining what is in a person's best interests, people must consider the person's past and present wishes and feelings and, in particular, any relevant written statement made when the person had capacity.

Lötjönen (2003), who investigated the regulation of clinical medical research on decisionally impaired adults in Europe, found no reference to advance directives in the following laws:

- Finland: Medical Research Act (1999)
- Denmark: Act on Research Ethics Committees (1988)
- France: Act on the Protection of Persons Undergoing Biomedical Research (1988)
- Netherlands: Act on Medical Research Involving Human Subjects (1998)

In addition to general conditions governing the participation of people in research, the Convention on Human Rights and Biomedicine<sup>8</sup> (article 17) has conditions which must be met before people who are unable to consent can participate<sup>9</sup>. These are that:

- The results of the research have the potential to produce real and direct benefit to his or her health;
- Research of comparably effectiveness cannot be carried out on individuals capable of giving consent;
- The necessary authorisation..... has been given specifically and in writing;
- The person concerned does not object.

Exceptionally, non-therapeutic research is permitted provided that two additional conditions are fulfilled, namely:

- The research has the aim of contributing, through significant improvement in the scientific understanding of the individual's condition, disease or disorder, to the ultimate attainment of results capable of conferring benefit to the person concerned or to other persons in the same category or afflicted with the same disease or disorder or having the same condition;
- The research entails only minimal risk and minimal burden for the individual concerned.

<sup>8</sup> Council of Europe (1997), The 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

<sup>9</sup> On 30 June 2004, 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 are available at: [www.coe.int/bioethics](http://www.coe.int/bioethics)

This last condition is fairly restrictive and rules out certain procedures, which could be particularly useful. Positron emission tomography (PET) scans, for example, can be viewed as having greater than minimal risk for people with dementia because:

1. They are invasive;
2. They carry the risk of pain and discomfort during and after;
3. Complications can require surgery to correct (Berghmans, 1998).

More recently, the International Ethical Guidelines for Biomedical Research Involving Human Subjects (2002)<sup>10</sup> allows slightly more flexibility with regard to risk when research involves individuals who are not capable of giving informed consent, including vulnerable groups such as those with varying degrees of dementia. Guideline 9 states:

“When there is ethical and scientific justification to conduct research with individuals incapable of giving informed consent, the risk from research interventions that do not hold out the prospect of direct benefit for the individual subject should be no more likely and not greater than the risk attached to routine medical or psychological examination of such persons. Slight or minor increases above such risk may be permitted when there is an overriding scientific or medical rationale for such increases and when an ethical review committee has approved them.”

Nevertheless, there are no internationally agreed criteria for precisely defining what constitutes a slight or minor increase above risks attached to routine medical or psychological interventions.

### 3.4.3 Problems and shortcomings of advance directives for dementia research

Few people actually write advance directives for future care (Emanuel et al. 1991). However, Schiff et al. (2000) found that many older people were interested in living wills even though they had little previous knowledge of this concept. Nevertheless, as there is little public interest and awareness of advance directives for participation in research, it is likely that even fewer people make such advance directives and fewer again would make an advance directive for participation in non-therapeutic research (Berghmans, 1998).

Consequently, in order to have a sufficient number of subjects for non-therapeutic research involving people with dementia, it is necessary to talk to the potential subjects about it whilst they are sufficiently capable of making a decision. Unfortunately, many people are only diagnosed with dementia at a later stage when they are not sufficiently able to understand what is involved and what the implications might be of making such an advance directive. Finding out that one has dementia is often a time of worry and stress, which for some people might not be the best time to start thinking about taking part in research projects. People with dementia would perhaps be more willing to take part in experimental treatment if treatments of proved efficacy have not had the desired effect. Unfortunately, by that

<sup>10</sup> Prepared by the Council for International Organizations of Medical Sciences (CIOMS) in collaboration with the World Health Organization (WHO) – Geneva, 2002.

time, they might not have sufficient capacity to consent or to write an advance directive (Lötjönen, 2003).

According to Berghmans (1998), a high level of decision-making capacity is needed to give valid consent to participation in future non-therapeutic research involving more than minimal risks or burdens. He questions whether people even in the early stage of dementia would satisfy such a demanding criterion. Moreover, people with dementia may be susceptible to the therapeutic illusion whereby they concentrate on possible benefits and ignore or underestimate possible disadvantages. If the research is proposed by the doctor responsible for the care of the person with dementia, the distinction between care and experiment may become blurred even if the research is clearly non-therapeutic (Gezondheidsraad, 2002).

Writing an advance directive for care/treatment is more straightforward than writing one for research. For the former, the person can refer to specific known interventions or use more general terms such as “all life-saving interventions” whereas for the latter, it is difficult to give consent for a future experiment which has not yet been devised and which by the nature of research is likely to be innovative. Berghmans describes advance directives for care/treatment as having a stronger moral and legal force. He states, “This is because the negative rights to privacy, bodily integrity and self-determination (as evidenced by laws on assault and battery) lay stronger claims on others than the positive willingness to be a potential subject in scientific research” (Berghmans, 1998).

Furthermore, it would be difficult to formulate wishes in terms that are neither too vague nor too restrictive. In view of the amount of time that could pass between making the advance directive and the research starting, it is difficult for someone to have a clear idea of what they might be letting themselves in for. Berghmans warns that, if one were to adopt Dworkin’s position, it would be theoretically justified to subject a refusing or resisting person with dementia to research interventions for which the former competent self gave advance consent because doing so would be in his/her critical interests (which would incidentally be contrary to the Convention on Human Rights and Biomedicine).

Berghmans proposes the involvement of proxies in the decision-making process. He suggests that proxies could discuss the issue with the person with dementia, speak to the researchers about interpretation of the advance directive, monitor the research process and signal any problems. However, it must be borne in mind that proxy decision makers may have different views about research than the person they are representing. Moreover, they are supposed to act in the person’s best interests or at least not act against them, which would be problematic in the case of non-therapeutic research involving more than minimal risks and/or burdens.

Another problem linked to consent to research (through an advance directive), particularly in the later stages of dementia, is that many potential subjects would by

that time be in an institutionalised or semi-institutionalised setting. Consent given in such a setting could, according to Lötjönen (2003), lack genuine voluntariness in that the person may feel vulnerable, at the mercy of the care staff and/or want to please the treating physician. The illness itself not only affects their decision-making capacity but also makes people with dementia dependent on others.

Berghmans concludes that enthusiasm surrounding the use of advance directives in the context of dementia research should be tempered. He feels that at most, they could be used in addition to the involvement of proxy consent and current subject consent – but not instead of.

## 3.5 Legal issues

### 3.5.1 Consent to treatment

In a medico-legal context, the right to self-determination finds its expression in the concept of consent. Laws governing consent to medical treatment are therefore extremely important and failure to respect them may lead to charges (e.g. of battery, assault or negligence, depending on the circumstances and the country in which it occurs). Referring to a well-known case in the UK involving the sterilization of a mental patient in 1990 (*Re F - a mental patient: sterilisation*, 1990 2 AC 1), Lord Goff stated,

“I start with the fundamental principle, now long established, that every person’s body is inviolate [...] Furthermore, in the case of medical treatment, we have to bear well in mind the libertarian principle of self-determination which, to adopt the words of Cardozo J (in *Schloendorff v Society of New York Hospital* (1914) 211 NY 125 at 126), recognises that – Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient’s consent, commits an assault” (in Kennedy and Grubb, 1994, p88).

Consent to treatment is also linked to human dignity, personal liberty and the inviolability of the person. Such values which can commonly be found in the preambles of international instruments relating to human rights such as the United Nations Charter, the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights. Similar references can be found in the constitutions of numerous countries. Examples include:

- Bulgaria: Everyone is entitled to personal freedom and inviolability. (Article 30.1)
- Hungary: Everyone has the inherent right to life and to human dignity. (Article 54.1)
- Latvia: The State shall protect human honour and dignity. (Article 95)
- Lithuania: The person shall be inviolable; Human dignity shall be protected by law. (Article 21, 1-2)
- Netherlands: Everyone shall have the right to inviolability of his/her person. (Article 10.1)

- Poland: The inherent and inalienable dignity of the person shall constitute a source of freedoms and rights of persons and citizens. It shall be inviolable. (Article 30)
- Portugal: The moral and physical integrity of the person is inviolable. (Article 25.1)
- Romania: The right to life, as well as the right to physical and mental integrity of person, is guaranteed (Article 22.1).
- Spain: Everyone has the right to life and to physical and moral integrity... (Article 15).

According to Justice Robbins JA, "Competent adults....are generally at liberty to refuse medical treatment even at the risk of death. The right to determine what shall be done with one's own body is a fundamental right in our society. The concepts inherent in this right are the bedrock upon which the principles of self-determination and individual autonomy are based" (In Kennedy and Grubb, 1994, p.89).

For consent to be valid, there are four main considerations:

1. Whether the patient has capacity (i.e. is competent to consent);
2. Whether the patient has been provided with appropriate information;
3. Whether consent was given voluntarily;
4. Whether the decision has been consistently expressed over time (although it should also be possible for a person to change their mind at any time).

With regard to the first condition, the fact that a person has dementia does not automatically mean that he/she is unable to give legally valid consent. As stated earlier, a person may have capacity in one domain and not in another, or he/she might have capacity in some areas of a particular domain e.g. with regard to making healthcare decisions, he/she might be capable of deciding whether to take a pain killer but not whether to undergo an operation involving considerable risk.

In 1995, the British Medical Association and the Law Society outlined certain criteria which might indicate whether a person had the capacity to consent to treatment. They stated that to demonstrate capacity individuals should be able to:

- Understand in simple language what the medical treatment is, its purpose and nature and why it is being proposed;
  - Understand its principal benefits, risks and alternatives;
  - Understand in broad terms what will be the consequences of not receiving the proposed treatment;
  - Retain the information for long enough to make an effective decision;
  - Make a free choice (i.e. free from pressure)
- (British Medical Association/The Law Society, 1997, p.66).

Concerning the provision of information, it is not sufficient to provide patients with information that they are capable of understanding. Doctors should do whatever is necessary to ensure that they have understood.

### 3.5.2 Legal recognition of advance directives

#### 3.5.2.1 *America*

As stated earlier, the concept of advance directives was developed in America in the 1970s following the proposed text by Luis Kutner in 1969. A significant milestone was reached with the 1991 Patient Self Determination Act which states that all States should recognise advance directives and furthermore, that all institutions receiving aid from Medicare/Medicaid should provide information and training to patients and providers concerning the use of advance directives (Phipps, 2003).

#### 3.5.2.2 *Australia*

In Australia, there are five States which have legislation providing for advance directives:

- Victoria: Medical Treatment Act (1988)
- Northern Territory : Natural Death Act (1988)
- Queensland: Powers of Attorney Act (1998)
- Australian Capital Territory: Medical Treatment Act (1994)
- South Australia: Consent to Medical Treatment and Palliative Care Act (1995)

With the exception of Queensland and South Australia, advance directives cannot cover the refusal of palliative care such as pain relief and the provision of food and water. In the Northern Territory, the refusal of treatment is limited to the case of terminal illness and in Queensland and South Australia to terminal illness or a persistent vegetative state (Biegler, 2000).

Doctors who provide treatment despite a valid refusal in the form of an advance directive may be charged with the statutory offense of medical trespass. Doctors who comply with advance directives in good faith are protected from criminal and civil liability (Biegler, 2000).

#### 3.5.2.3 *European convention, principles and recommendations*

There are a few documents which refer either directly or indirectly to advance directives, which whilst not actually laws, may well have been influential in guiding national laws in the health care domain. In 1994, for example, the WHO Regional Office for Europe endorsed a document entitled “Principles of the Rights of Patients in Europe”<sup>11</sup>. Article 3.3 of these principles states:

“When a patient is unable to express his or her will and a medical intervention is urgently needed, the consent of the patient may be presumed, unless it is

<sup>11</sup> WHO, Declaration on the promotion of patients’ rights in Europe – Amsterdam, March 1994.

obvious from a previously declared expression of will that consent would be refused in the situation.”

A number of countries, the majority of which do not have any legislation on advance directives, have ratified the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine<sup>12</sup> (known as the Convention on Human Rights and Biomedicine). These are Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Georgia, Greece, Hungary, Iceland, Lithuania, Moldova, Portugal, Romania, San Marino, Slovakia, Slovenia, Spain and Turkey. 12 countries have signed the Convention but not yet ratified it.

Article 9 of the Convention on Human Rights and Biomedicine states:

“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” (Article 9).

Another European provision covering previously expressed wishes is the Council of Europe’s recommendation<sup>13</sup> on principles concerning the legal protection of incapable adults which points to the need to balance the previously expressed wishes with those currently expressed:

“In establishing or implementing a measure of protection for an incapable adult the past and present wishes and feelings of the adults should be ascertained so far as possible, and should be taken into account and given due respect” (Principle 9).

#### **3.5.2.4 Europe**

Despite growing awareness and use of advance directives in Europe, actual legislation has not been very quick to follow. Most laws containing a reference to advance directives were passed in the last 15 years.

One exception is the Austrian Federal Hospital Law of 1957 (KAG). Paragraph 10 of this law states that in hospitals and clinics, it is obligatory when recording a patient’s case history to document instructions from the patient regarding certain forms of treatment which should not be carried out in the event of future incapacity. These instructions should be taken into consideration at any point in the future when a relevant medical decision has to be made. There is no direct reference to an advance directive in the form of a document (in view of the fact that the concept of advance directives was not really developed until the early 1970s) although such documents would presumably be valid in this context.

In the Netherlands, the Medical Treatment Contracts Act of 17 November 1994 (WGBO) contains a reference to advance directives. Article 450 of this act states that if a patient who is over 16 years of age and incapable of reasonably assessing his/her interests with regard to care, care providers must comply with his/her apparent opinion expressed in writing while still capable of reasonable assessment.

<sup>12</sup> Council of Europe (1997), The 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.

<sup>13</sup> Council of Europe: Recommendation no. R (99) 4 of the Committee of Ministers to Member States on principles concerning the legal protection of incapable adults.



Care providers are not, however, legally bound by this statement and may deviate from it, if there are good reasons for doing so.

Hungary, Belgium and Georgia all have laws which grant people the right to express their wishes for medical treatment in advance of incapacity. The Law on the Rights of Patients (2000) of Georgia grants citizens the right to express in advance and in writing their wishes with regard to the consent to or refusal of resuscitation, life-saving treatment or palliative care. Such advance directives are only valid if a person's condition is caused by the terminal stage of an incurable disease or a disease which will inevitably cause serious disability. In Hungary, the Health Act (1998) allows people to prepare a written statement, an advance directive, to be used in the event of unconsciousness or incapacity in which they can refuse specific forms of treatment. The Belgian Law of 22 August 2002 relating to the rights of patients states that if a person with capacity declares in writing his/her refusal of a particular treatment proposed by a medical practitioner, the refusal must be respected from that point on unless the patient revokes it (at which time, he/she must have capacity to do so).

In Finland, the Act on the Status and Rights of Patients (1992) states that the "previous wishes of the incompetent patient shall be taken into account by the legal representative or next of kin making decisions on behalf of the patient." With regard to emergency treatment, it is further stated that the patient should not be treated against their will, if they have indicated this in a valid advance directive. The first statement is actually part of an amendment to the 1992 act (amended in 1999) which was intended to fulfil the requirements of the Convention on Human Rights and Biomedicine. These provisions are currently being reviewed by the Ministry of Social Affairs and Health (Lötjönen, 2003, p. 379).

In Denmark, the Law on the Legal Status of Patients (1998) provides very precise details on the use of advance directives. In chapter 3, it is stated that an advance directive may specify that:

1. Life supporting treatment would not be desired if the testator were facing unavoidable death;
2. Life supporting treatment would not be desired in case of illness, advanced debilitation due to old age, accidents, heart failure or similar situations that cause such a severe invalidity that the testator would be permanently unable to take care of themselves physically and mentally.

Life supporting treatment is described as meaning treatment where there is no outlook for cure, improvement or alleviation but only to a certain prolongation of life. The Danish Law also has provisions covering the registration and consultation of advance directives. Health professional who are considering giving life supporting treatment to a person who is unable to consent must consult the Will Registry to check whether the person has made one. Wishes in line with number 1 above

are legally binding and must therefore be respected whereas wishes in line with number 2 above are merely advisory but must be registered in the medical notes.

In Spain, the Basic Law 41/2002 regulating patient autonomy allows for capable adults to make care and treatment decisions in advance of their possible loss of capacity and also to name a proxy. The law does not state what can or cannot be included in the advance directive but stipulates that instructions cannot be against the law, contrary to “*lex artis*” (good medical practice) or no longer correspond to what the person originally anticipated. Advance directive registries exist in some of the autonomous regions and legislation is pending to create a registry at national level.

In England and Wales, the Mental Capacity Act 2005 provides a statutory framework for people who are unable to make decisions due to mental health problems, learning disabilities or the consequences of illness or disease such as dementia. The Act contains a section on advance decisions to refuse treatment which, if valid and applicable, are legally binding.

In other countries, the situation is less clear in that the use of advance directives is not covered by legislation. Nevertheless, in some cases advance directives containing a refusal of treatment may still be considered as being legally binding.

In the Adults with Incapacity (Scotland) Act 2000, an advance refusal does not seem to have a direct effect. Rather, the patient needs to ensure that the person who will be his/her guardian/welfare attorney is aware of his/her wishes and it is the refusal of the guardian/welfare attorney of the treatment in question that is binding – subject to appeals procedures etc. The Mental Health (Scotland) Act 2003 introduces advance statements on treatments for mental disorder, which are binding, but with very broad safeguards which allow them to be disregarded with relative ease.

In Switzerland, laws exist at the regional/cantonal level in a few regions/cantons (Council of Europe, 2003). However, according to Wolfensberger (2004), a reform of the guardianship law in Switzerland is currently underway which may lead to legal recognition of advance directives in the near future. Similarly, a law proposal on palliative and end-of-life care has been presented to the Parliament in Luxembourg which, if successful, will lead to legal recognition of advance directives. In Italy, a bill (No. 4121) was presented to the Chamber of Deputies on 30 June 2003 which deals with advance directives and health care.

In Sweden, although there is no law, the Swedish National Board on Social Affairs has produced recommendations which state that the earlier wishes of patients must be respected in end-of-life decision-making (Lötjönen, 2003). Similarly, according to the National Ethics Committee of Luxembourg (Avis 1/98), advance directives are not legally binding but may be used in helping doctors make decisions.

Germany has no statutory provisions comprehensively regulating patient's instructions and advance directives. However, an advance directive may in certain circumstances be considered as binding e.g. if there is no indication of a change of will related to the specific situation and if the instruction is based on sufficient medical information for the medical treatment proposed. In such cases, a decision that is clearly in favour of withdrawing treatment and is clearly the manifest desire of the patient must be complied with (Council of Europe, 2003). Generally speaking, advance directives in Germany containing decisions about future care are expected to be used by doctors in order to determine the patient's will in case of incapacity. If a doctor treats a patient, despite the patient's refusal of such treatment (as expressed in an advance directive), he/she may be charged with physical injury.

### 3.5.3 Health care proxies

The family often plays an important role in decision-making in the case of incompetent people. However, their role in the decision-making process is far from clear. Whilst their views are often sought, particularly when it is impossible to know that the patient would have wanted, generally speaking this is not legally binding. Moreover, it is one thing to consent to treatment that they consider necessary, in the patient's best interests or in accordance with their known wishes, and quite another to request a doctor to stop treatment (Hertogh and Ribbe, 1996). A specific health care proxy is appointed by a person prior to losing capacity or by a court after the person loses capacity. As such it differs from general guardianship measures organised on behalf of the person with incapacity, which are rarely limited to health care decisions and do not always have the same degree of freedom with regard to the choice of the substitute decision maker.

In some countries, people are allowed to designate another person to take care or medical treatment decisions on their behalf when they no longer have the capacity to do so themselves. In America, for example, most advance directive forms contain a document with the person's care/treatment wishes and another document in which a person is named who will be responsible for making such decisions. In America, this person may be called an attorney for health care or a health care surrogate, proxy or agent.

In Europe, various laws also provide for the appointment of a health care proxy e.g. the Law of Georgia on the Rights of Patients (2000), the Hungarian Health Act (1998) and the Spanish Law (14/2002) regulating patient autonomy. An amendment in legislation in 1998 made the appointment of health care proxies possible in Germany<sup>14</sup> (Lötjönen, 2003). In Ireland, under the Powers of Attorney Act (1996), an attorney can be appointed whilst someone still has capacity and this attorney continues to be valid even when the former no longer has capacity. Unfortunately, the powers of the attorney do not extend to decisions linked to medical treatment although they do cover certain care-related decisions. In Scotland, however, the Adults with Incapacity (Scotland) Act 2000 allows people to appoint welfare powers of attorney who

<sup>14</sup> §§ 1904 II and 1906 V of the "Bürgerliches Gesetzbuch".

can make treatment decisions on their behalf which are legally binding (subject to appeals procedures etc.).

More recently, laws on patients rights, which came into force in 2002 in Belgium and France, allow for the advance appointment of proxies (known as the “proxy designated by the patient” and the “person of trust” respectively).

Finally, the Mental Capacity Act 2005 (applicable in England and Wales) gives people the right to appoint a lasting power of attorney to act on their behalf in case of future incapacity. The Act also saw the creation of “independent mental capacity advocates” who support and represent people lacking capacity who have no one else to speak for them when decisions need to be taken about serious medical treatment and long-term residential care.

#### **3.5.4 Determining the validity of advance directives**

As with consent to treatment in general, for an advance directive to be valid, certain criteria must be fulfilled. This may vary from one country to the next, but the following is commonly expected:

- **Competence:** The person must understand the nature, purpose and likely consequences or implications of the treatment when making the decision to refuse it or consent to it.
- **Applicability:** The AD must cover the current circumstances. Sometimes, it may be unclear whether the person had particular circumstances or a particular situation in mind when he or she wrote the advance directive.
- **Undue influence:** A decision to refuse treatment must be free from the undue influence of others. Other kinds of influence might include pain and the influence of drugs/medication.
- **Current relevance:** The advance directive should truly represent the person’s most recent wishes.

### **3.6 Personal and practical issues**

#### **3.6.1 Reasons for writing an advance directive**

People choose to write advance directives for a number of different reasons. For some, it is because they do not want to be kept alive artificially, do not want to undergo treatment for which there is no hope for recovery or an improvement in their condition and/or do not want to have their suffering prolonged. This is often coupled with the desire to avoid being a burden on others and the desire to control their own lives. Others worry about being treating against their wishes or on the contrary not receiving the treatment they would like. Quality of life judgements and fears about loss of dignity are also important.

For many people, the above reasons are linked to their perception of dementia, which may derive from personal experience of a friend or relative or from the wider society in which they live. However, the experience of dementia differs from one person to the next. There is perhaps a tendency to concentrate on neurological factors and their consequences, but as Dresser (1995) points out, “Not everyone finds it frightening, leads an unhappy existence or exhibits distress and misery. For some patients, the quality of life is largely dependent on their social and physical environments, as opposed to the neurological condition itself.” It is therefore important that people are provided with an accurate picture of dementia which is neither positively nor negatively biased as this may well affect their decision-making.

Another important factor to bear in mind is the state of mind of the person writing the advance directive. A person who has just been informed of the diagnosis of dementia may be experiencing different emotions such as anger, fear or denial. They may also be depressed or have feelings of hopelessness. Unfortunately, the longer the person waits before writing the directive, the greater the chances are that their capacity deteriorates. For this reason, access to counselling, in either its general or specific senses, in the early stages of dementia is important. On the other hand, people with capacity often have to consent to treatment in a context of fear, worry or even severe pain, which in many cases are unavoidable.

When writing an advance directive in the case of dementia, people should be aware of the fact that decisions about life-sustaining interventions may arise at any point in time, not just in the later stages of the disease. They may need to make decisions about routine or serious but not-life threatening conditions as well.

### **3.6.2 Reasons for not writing an advance directive**

With regard to people who decide not to write an advance directive (presuming they are aware of what one is), there are a few possible explanations (High, 1993; Phipps, 2003):

- Procrastination
- Expect others to take the initiative e.g. doctors
- Don't know how to go about it
- Find it inconvenient
- Don't trust a piece of paper
- Don't think that it is necessary as they trust the family or doctors to make decisions
- Feel that it is too early to start thinking about that kind of thing
- Find the issue distressing (for themselves and/or their family)
- Don't want to think about such issues

Concerning the expectation that doctors will raise the issue, Rubin et al. (1994) found that some doctors are afraid that patients might interpret a discussion about advance directives as a subtle hint that their condition is poor or that the doctor is unwilling to provide maximal therapy. It is unclear whether this fear is warranted. An earlier study carried out by Emanuel (1991) found that patients generally welcome the opportunity to discuss advance directives with health care professionals. A study carried out in 2000, involving patients enrolled in cardiovascular resuscitation programmes, found that 96% of patients would find discussions about advance directives initiated by doctors acceptable, whereas only 4% would find such discussions too anxiety provoking to pursue (Heffner and Barbieri, 2000).

### **3.6.3 Racial and cultural issues**

A study carried out in America by Hopp and Duffy (2000) revealed significant differences between white and black people with regard to end-of-life decision-making. They found that white people were significantly more likely than black people to discuss treatment preferences before death, to complete a living will and to appoint a health care proxy. Black people were more likely to want life-prolonging treatment and to choose aggressive treatment even if permanently unconscious. Hopp and Duffy suggest that there may be a tendency among black people in America to see advance directives more as a means of limiting end-of-life care rather than as a means of ensuring control over future medical care through autonomous decision-making. They add that an earlier study found that seriously ill black people were in fact less likely to receive intensive care so such a view might not be unrealistic.

The situation and characteristics of the black population in America is probably very different to that of black and other races of people living in Europe. There may, however, be other groups of people who see the principle of advance care planning and the potential of advance directives differently. Consequently, it is necessary to bear in mind the possibility of racial and cultural differences when organising an awareness campaign for advance directives or when approaching people about end-of-life decisions. It may be necessary to investigate possible racial or cultural differences on a national basis.

With regard to the provision of basic care (i.e. bodily cleanliness, pain relief and direct oral nutrition and hydration) as recommended by the Law Commission in the UK, Dimond (2000) points out that this could go against the wishes of certain groups such as Buddhists, who might not be in favour of receiving sedatives or medication for pain relief.

### **3.6.4 Arguments against the use of advance directives**

One argument against the use of advance directives is that they involve making informed decisions about future medical care or treatment. As one cannot know what all the risks and consequences might be at some time in the future, one cannot really be said to be informed. Furthermore, in the time between writing the advance directive and it coming into effect, people will have been deprived of more

recent knowledge about treatment options. Also, it is not always clear whether the person who wrote an advance directive was accurately informed or whether their decision was to some extent influenced by false information they had previously acquired e.g. the myth that most patients in cardiac arrest end up in a persistent vegetative state (Sanders, 1999).

Medical treatment decisions are seldom one-off choices of action. They often involve a number of stages, each involving consultation with the patient. Between the stages, a person's clinical condition may change, his/her understanding of the real and potential implications of the treatment may develop and he/she may experience physiological or psychological effects. A person making an advance directive is deprived of this information and experience (British Medical Association, 1995).

People with capacity sometimes assume that they understand what they are declining when it is not actually the case. As pointed out by Loewy (2004), "Patients who state that they would never want to be on a ventilator often do not understand what a ventilator is and that it can be used as a temporary measure (as during anaesthesia or to tide a patient over during a severe bout of pneumonia), as a permanent necessity (...) or as a comfort measure (in pulmonary oedema or advanced COPD)."

Another problem with advance directives is that people tend to change their minds about all kinds of things (e.g. politics, religion, relationships, etc.) and there is no reason to believe that this should be different when it comes to making decisions about health. Clearly, healthy people might not make the same decisions as those who are ill (Nys, 1997). As Schneiderman (1992) points out, fear, pain or a sense of hopelessness might cause some patients to temporarily resist highly promising resuscitative measures. Conversely, an initially enthusiastic patient, after experiencing the relentless progression of a burdensome disease, might begin to have different thoughts about life prolongation.

On the other hand, in the case of dementia, people tend to be older. Statistics show that older people have generally had more personal contact with medical professionals and health-care institutions. In addition, they generally have some personal experience of death, grief, loss and suffering. Many have dealt with or come into contact with end-of-life issues either personally or through friends and relatives. For this reason, although they may still change their minds in the course of the disease, their advance decisions about end-of-life issues are more likely to be founded on a better and more mature understanding of the issues involved (Vollmann, 2001).

Nevertheless, it is still important to regularly update advance directives in order to ensure that when they are used, they are an accurate representation of one's more recent views. Unfortunately, in the case of dementia, it could happen that the advance directive is only referred to many years later. The treating medical staff may be unsure as to whether the views expressed in the advance directive are still valid,

particularly as medical treatments may have progressed to the point that they no longer reflect the situation described by the author (Nys, 1997).

Although writing on the subject of euthanasia, The Danish Council of Ethics (2003) make an interesting point which could apply to writing advance directives covering life-sustaining or life-saving treatment, namely that the compulsion to choose may actually restrict patients' autonomy by overburdening them with difficult decisions at a time when they are least able to cope with it. They point out that choosing between life and death is an enormous task and a great responsibility to impose on a person in a very difficult situation to start with. They may want to try to balance the interests and needs of the family with the advice of their doctor and this at a time when they may be experiencing fear, despair, a sense of hopelessness and the feeling of being a burden to others. Of course, there is no obligation to write an advance directive but were they to become more common, some people would feel under pressure to address certain issues that they would otherwise prefer not to.

A problem may arise in the case of iatrogenic injury i.e. when it is the treatment rather than the underlying illness that threatens the patient. For example, a patient might stop breathing whilst sedated or develop anaphylaxis due to the administration of an antibiotic. In such cases, Sanders (1999) suggests, "it would be prudent to err on the side of life and institute resuscitative treatment and procedures."

Another problem is that in areas where palliative care is not very well developed, people may see the refusal of life-saving or life-sustaining treatment as more or less the only valid option. It would be highly undesirable if the use of advance directives undermined either directly or indirectly the pressing need for significant improvements in the long-term and terminal care of those with dementia.

### **3.6.5 How specific or vague should advance directives be?**

Advance directives are intended to provide clear and convincing evidence of a person's wishes with regard to medical treatment or care at a time in the future when they are no longer capable of making such decisions. However, there are conflicting opinions as to how specific or vague an advance directive should be. On the one hand, a very detailed and specific advance directive should leave medical staff in no doubt as to what the author would have wanted, but on the other hand, the document would risk being so specific that it would be unlikely to ever apply fully to a particular situation as there are so many different possibilities and variations.

At the other extreme, advance directives containing vague terms can also be problematic, e.g. those containing terms such as "no reasonable expectation of my recovery", "terminal illness", "irreversible disease", "heroic measures" and "artificial means". Such ambiguous terms may make it difficult to determine how a particular advance directive should be interpreted in a particular clinical setting.



As Basta (2003) points out, “A stroke, even crippling, cannot be characterized as a terminal illness. The application of a ventilator to assist in the treatment of a potentially curable pneumonia can hardly be considered as “heroic”, and the term “artificial means” is already too vague and could apply to any medical intervention, since most medical procedures in one way or another utilize artificial means.” Sanders (1999) questions whether pneumonia, congestive heart failure or renal failure are terminal illnesses. She argues that they are all treatable diseases but that if left untreated and sometimes even despite treatment, people may die of them. She points out that in medicine, medical staff tend to deal more with probabilities than certainties and that actual prognoses (e.g. in the case of stroke, myocardial infarction or cardiac arrest) may take a few days to be known.

Emanuel et al. (1991) investigated the use of an advance directive based on a variety of treatments and procedures for different health scenarios (coma with chance of recovery, persistent vegetative state, dementia and dementia with terminal illness). This has the advantage of allowing people to tailor their decisions to different situations as what a person might want if in a persistent vegetative state might well differ from what they would want in the case of dementia. However, Schneiderman et al. (1992) are critical of such an approach as it relies on patients making informed decision about treatments that they might not fully understand and also as it directs their attention away from values and goals (which they consider to be more important).

They propose the development of advance directive forms that allow patients to express their wishes in the context of a variety of clinical conditions in terms of quality of life. Vinen (2002) also states that there is a need to shift the focus of advance care planning from the acceptance (or rejection) of specific treatments to a focus on the outcomes of treatment, which should include a consideration of what is acceptable to the patient in terms of quality of life, burdens of treatment and likelihood of a good (or poor) outcome. Schneiderman et al. presume that patients are best placed to know under what conditions they would prefer not to be kept alive. The onus would then be on medical staff to provide the most suitable treatment, in the light of their expert knowledge and experience, to meet the patient's wishes. For a sample form, please see Schneiderman et al. (1992). However, they acknowledge that there may be a risk that such an advance directive does not provide sufficiently “clear and convincing” wishes about specific treatment options (as with vague terminology).

Furthermore, such an approach relies on medical staff being able to accurately interpret quality of life issues alongside medical treatment outcomes. Clearly, quality of life decisions should be made from the perspective of the individual patient concerned. This is a difficult task as two people in identical clinical states may have different views about the quality of life in the light of their different values and preferences. Hence, it is important that doctors have information to enable them to judge what constitutes quality of life for the person concerned.

### 3.6.6 Statements of values

Just as a personally appointed health care proxy, who is familiar with one's background, preferences and values, can help interpret an advance directive where it is unclear what the author would have wanted in a particular situation (either because it is not covered by the advance directive or the advance directive is too specific or vague), so too can a statement of values provide valuable information about what is important and meaningful in life for the author.

Statements of values are a series of statements (or answers to questions) which provide background information on what is important to someone i.e. on their values and preferences. The information in a statement of values may be more detailed than in an advance directive, is not phrased in legal terminology and is not directly limited to specific medical treatment. It is not a legal document but can provide valuable information that may be extremely useful when it comes to interpreting an advance directive.

Alzheimer Europe has produced a form with suggestions for the kind of information that could be included e.g.

My spiritual and philosophical beliefs:

Here I put down the spiritual or philosophical beliefs or principles that are important to me in my life.

Here I put down what, if any, religion I belong to, and what importance religion has in my life generally.

What makes life worth living:

Here are some of the things that give special meaning to my life, including things about my health and welfare, relationships, work, leisure, art, sport and recreations. These are the things that make me the sort of person I am.

Statements of values may take some time to complete as they can be fairly lengthy and require more philosophical responses than advance directives, but they may contain very useful information which could help others to better understand the author's choices and come to terms with certain decisions made. Such documents are likely to contain very personal information and for this reason, people should think carefully about where to keep them and who should receive a copy. Some people might prefer to write such documents alone, whereas for others it might serve as a means to talk about certain issues in the context of family or friends.

### 3.6.7 The "trial option"

Research carried out by Reilly et al. (1994) into treatment preferences for 4 scenarios (coma, terminal illness, Alzheimer's disease and usual health) revealed that many people preferred to use a "trial" treatment option for certain scenarios (but not for antibiotics in the case of Alzheimer's disease). The trial option was defined as follows: "use of the therapies.....for a period of time adequate to determine whether

you were receiving significant benefit from them or not.” The authors suggest that people would be more at ease consenting to treatment if they knew in advance that it would be discontinued should it turn out to be ineffective or of no benefit to them. They suggest that it might enhance patients’ autonomy and therefore be beneficial to include a trial option in advance directives. Reilly et al. also point out that should the trial procedure ever be adopted, it would be necessary to fix the stopping rules. They propose rules based on beneficence (i.e. decided by the doctor) or on autonomy (i.e. to be fixed in advance by the patient).

### **3.6.8 Advance care planning**

Ideally, the writing of an advance directive should not be thought of as simply signing a document containing preferences. On the contrary, it should be seen in the context of advance care planning which may or may not result in the production of an advance directive. Five steps have been identified which could serve as a guideline for advance care planning (in Taylor and Cameron, 2002):

1. Raising the topic and giving information
2. Facilitating a structured discussion
3. Completing a statement and recording it
4. Periodically reviewing and updating the directives (if possible)
5. Bringing prior wishes to bear on actual decisions

In the case of dementia, the first step could be taken by medical staff involved in the diagnosis or by Alzheimer Associations, either directly if carers or the person with dementia contact them or indirectly through awareness-raising campaigns. Alzheimer Europe is currently investigating how best the Alzheimer associations can be involved around the time of a person’s diagnosis. People should then be provided with the kind of information that they need in a way that they can understand it. For some people, it might help to provide them with printed information, but this should usually only be an adjunct to a proper discussion of the issues. They should take the necessary time to assimilate this information. It will usually also be helpful for some people to involve family and friends in this process, and particularly a health care proxy if one has been or is to be appointed.

The advance directive should be completed (using pre-prepared forms if necessary according to measures in place in the country where the person lives) and recorded in the appropriate manner. Some countries have a system in place. For example, in Denmark, advance directives must be registered at the central Will Registry which doctors are obliged to consult before treating a patient who is unable to consent. In Luxembourg, a law proposal on palliative care stipulates that a copy of the advance directive should be sent by registered mail to the Ministry of Health. In countries where there is no system, it would perhaps be wise to give a copy to one’s family doctor, to trusted family members, to the health care proxy (if one has been appointed) and to a lawyer. In any case, the advance directive or information

concerning its whereabouts, should be kept in the person's medical file and be available in case he/she is ever admitted to hospital for treatment.

With regard to the review and regular updating of the document, as a person's capacity progressively diminishes in the course of the disease, there will come a time when it is no longer possible to update the advance directive. For this reason, advance directives may be fairly old by the time they are actually used but this is unavoidable in the case of dementia.

The final step involves making sure that the advance directive is actually produced and referred to at the appropriate time. This must be thought about in advance particularly if there is no system in place to regulate this matter. In emergency situations, medical staff are unlikely to have the time to make in-depth investigations into the possible existence of an advance directive. The onus to ensure that they are aware of the document will usually rest with relatives, friends, a health care proxy, a solicitor, or, where the treatment is taking place in hospital, the general practitioner<sup>15</sup>.

## **3.7 Medical issues**

### **3.7.1 The extent to which doctors should/do follow advance directives**

In the section on legal issues, the extent to which advance directives are legally binding or merely advisory was discussed. However, irrespective of whether an advance directive is legally binding or advisory, doctors have to have easy access to such documents, be sure that the author fulfilled the necessary criteria for writing such a document and be able to accurately interpret the instructions contained therein. This does not mean that doctors are then obliged to follow the instructions. In the explanatory report of the Convention on Human Rights and Biomedicine, it is stated:

“Taking previously expressed wishes into account does not mean that they should necessarily be followed. For example, when the wishes were expressed a long time before the intervention and science has since progressed, there may be grounds for not heeding the patient's opinion.”

Even if the instructions or wishes are clearly stated and applicable to the situation, a doctor may have moral/ethical objections to the patient's wishes or feel that they are not in the patient's best interests. In such cases, a doctor should not be obliged to comply with the patient's wishes but would be expected to arrange for a colleague to take over responsibility for the treatment of the patient. This might risk having a negative impact on the doctor-patient relationship but would guarantee that the patient's wishes were respected. However, it could be argued that doctors should abide by the law and therefore be obliged to comply with a legally binding advance directive if they cannot organise for a colleague to take over the patient's care.

<sup>15</sup> The term “general practitioner” is used to refer to a doctor whom patients consult in the first instance for any medical problem. If necessary, this doctor would refer a 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.

The possibility that a doctor may have different opinions from those of the patient, particularly on end-of-life treatment options, is worth bearing in mind when it comes to discussing the writing of an advance directive with one's doctor. On the other hand, presuming that the doctor acts in a professional manner, this should not affect advice given on different medical options. According to a study carried out by Markson et al. (1997) in America, 88% of doctors stated that, based on their entire career, the advance preferences of their patients for end-of-life care had often or very often been acceptable to themselves. A high percentage of patients had asked for information on the risks and benefits of different therapeutic options (91%) and for the doctor to recommend those that would be in their best interests (89%). Only 14% of doctors stated that they would try to persuade a patient to change their mind if a decision was incompatible with their own moral or religious beliefs and 71% said that they would be willing to follow a directive even if it were incompatible with their religious beliefs.

Nevertheless, doctors may need some kind of guidance on how to introduce and discuss the issue of advance directives with patients, as well as information on the legal status of advance directives and their obligations in this respect.

### **3.7.2 Emphasis on healing as opposed to accompanying the terminally ill**

In the past, the actual process of dying did not tend to last a long time and the concentration of doctors was on healing patients, but the advancement of medical science has resulted in dying sometimes becoming a long-lasting process. In many cases, doctors now have the means to prolong the experience of dying and are therefore regularly faced with terminally ill patients for whom there is no hope for recovery, but who thanks to medical progress may live for some time to come. Contact with such patients may also remind doctors of the inevitability of their own death. (Barolin, 2000)

Although there are clearly limits to medical science and death is inevitable, some doctors experience the death of patients as a kind of failure of medicine and in a certain sense of themselves. According to Dekkers (2001), "Many physicians believe that a patient is dying not because of the disease he or she is suffering from, but because there are no further medical or technological strategies available to keep the patient alive." Callahan describes this as follows:

"Death is not construed as an inevitable biological denouement but as a medical failure.... Death has been moved out of nature and into the realm of human responsibility." (Callahan, 1993, p.64)

Many doctors have received little if any training in how to deal with death and dying. In general, their training has concentrated on the healing side of medicine whilst neglecting the helping or accompanying side of medicine. Consequently, dealing with terminally ill patients may evoke in them feelings of failure, guilt and/or fear. Consideration should be given to measures that can help doctors and other professionals manage their feelings and reactions in such situations.



*The legal status  
of advance directives  
in European countries*

## 4 *The legal status of advance directives in European countries*

### 4.1 **Austria**

#### 4.1.1 **The legal status of advance directives in Austria**

Advance statements do not currently have legal status in Austria. However, according to §10 of the Hospital Establishment Law of 1957 (KAKuG), it is obligatory when recording a patients' case history in hospitals and clinics to document instructions from the patient regarding certain forms of treatment which should not be carried out in the case of future incapacity. These instructions must then be taken into account by doctors in the event of the patient's future incapacity.

It is possible for a competent person to appoint someone to make health care decisions on their behalf at a time in the future when they no longer have the necessary capacity to make health care decisions themselves.

In Austria, it is possible to write an advance directive (a "Patientenverfügung") and/or to appoint a trusted person to act on one's behalf ("Vorsorgevollmacht"). The duties of the trusted person may be limited to financial, administrative and/or care issues, but may also (or alternatively) cover health care decisions.

A draft proposal for a new law on advance directives was recently presented by the Ministry for Health and Women to the Austrian Parliament. According to a text accompanying the draft proposal, there is a general legal consensus that advance directives are legally binding provided that the person definitely had legal capacity at the time the document was written, was not under any pressure and that the advance directive refers to concrete health care situations. The proposed law would merely provide the necessary clarification of the legal situation.

#### 4.1.2 **Conditions surrounding the writing, validity and registering of an advance directive**

Anyone can write an advance directive. Printed forms exist but it is also possible to write one's own advance directive by hand. It is advisable but not obligatory to involve a lawyer or notary when drawing up an advance directive and/or appointing a health care proxy.

Capacity is presumed. In case of doubt, it is assessed by a doctor - either a doctor of the person's own choice or an independent doctor.

The person writing the advance directive must state their wishes clearly and be free from any physical, mental or social pressure. Furthermore, they must have been informed of the consequences of any refusal of treatment.

According to the law proposal, an advance directive can also be made orally by a hospitalised patient. For non-hospitalised patients who have not personally written or signed their advance directive, it must contain the signature of a doctor who certifies that he/she has provided the person with the relevant information relating to the decisions made by the patient.

There is currently no registration system for advance directives. However, in line with the law proposal, the creation of a national registry is foreseen which would keep a copy of the latest version of a person's advance directive. There are also plans for the electronic registration of advance directives.

An advance directive which was not written in a hospital or clinic is only valid for 3 years, after which time it can be renewed.

#### **4.1.3 What an advance directive can cover**

The health care proxy (the trusted person with responsibility for health care decisions) can make decisions covering:

- The treatment of straightforward medical conditions (for more complicated conditions/treatment, the approval of a court is necessary);
- The treatment of a psychiatric condition (for simple treatment only; if the person has been interned in a closed department or psychiatric institution, the law on forced internment would apply);
- Care and welfare decisions.

As health care proxies are supposed to make decisions that are in the interests of the person they are representing, the refusal of basic care would not be justified.

If the law proposal is successful, it will be possible for an advance directive to cover:

- The treatment of medical conditions;
- The treatment of a psychiatric condition;
- Life-supporting treatment and
- Life-saving treatment.

#### **4.1.4 Obligation to comply with instructions contained in an advance directive**

Doctors are currently expected to comply with instructions contained in an advance directive. According to the law proposal, in order to be legally binding, the advance directive must be clearly applicable to the person's health condition and the proposed treatment. If this is not the case, or if the advance directive has not been updated, it should be considered as being advisory.



#### 4.1.5 Amending, renewing and cancelling advance directives

According to the law proposal, an advance directive can be cancelled or amended at any time without any formal requirements or the necessity to provide justification. This can be done orally, in writing or through clear behavioural signs. If the advance directive was not written in a hospital or clinic, it must be renewed after 3 years.

If a person is no longer able to renew the advance directive, they can be assisted by the doctor responsible for their care or by an officially appointed patient representative. Advance directives made orally in a hospital lose their validity when the patient is discharged.

## 4.2 Belgium

### 4.2.1 The legal status of advance directives in Belgium

The Law of 22 August 2002 relating to Patients' Rights (article 8, paragraph 4) states that if a person, whilst still capable according to the terms of the said law, declared in writing his/her refusal of a specific form of treatment proposed by a medical practitioner, this refusal must be respected from that point on, unless he/she regains capacity and revoke it.

### 4.2.2 Conditions surrounding the writing, validity and registering of an advance directive

To make a valid advance directive, a person must have the necessary capacity to do so. The advance directive must be made in writing.

### 4.2.3 What an advance directive can cover

The Law relating to Patients' Rights mentions the refusal of a specific form of treatment. Article 14 further states that a person can appoint in writing in advance of incapacity a "mandataire désigné par le patient" (a health care proxy). A special mandate must be dated and signed by the proxy and the patient to confirm that the former is authorised and agrees to consent on behalf of the latter.

The Law on Euthanasia of 2002 allows doctors to perform euthanasia to patients who are unconscious or cannot express their will. In such cases, the patient must have made the advance directive for euthanasia within 5 years of having lost capacity and it must have been added to their medical file. The document must be written, dated and signed in the presence of two adult witnesses, and any appointed health care proxies. At least one of the witnesses must have no material interest in the person's death. Doctors must follow a certain procedure and respect certain conditions which differ from those concerning requests made by people with capacity.

#### **4.2.4 Obligation to comply with instructions contained in an advance directive**

The law states that an advance directive refusing specific forms of treatment must be respected provided that the person has not revoked it.

#### **4.2.5 Amending, renewing and cancelling advance directives**

An advance directive can be revoked at any time in writing by the person who made it.

### **4.3 Denmark**

#### **4.3.1 The legal status of advance directives in Denmark**

Advance directives have legal status in Denmark according to the Law on Patients' Legal Status (No. 482, 1998). They are legally binding in certain circumstances and advisory in others (please see section 4.3.4 for details). Some people express their future wishes in powers of attorney documents. Such wishes are not legally binding but may serve as guidelines for the attorneys who have been appointed.

#### **4.3.2 Conditions surrounding the writing, validity and registering of an advance directive**

Any person over the age of 18 who is not already under guardianship can write an advance directive. Capacity is presumed. It is not necessary to involve a doctor or notary.

There is a registration procedure in that advance directories must be sent to a Central Registry. The registration procedure currently costs about Euro 7.

The validity of advance directives is not limited to a set period of time.

#### **4.3.3 What an advance directive can cover**

Advance directives can include decisions relating to:

- The treatment of medical conditions and
- Life-supporting treatment.

but not life-saving treatment.

#### **4.3.4 Obligation to comply with instructions contained in an advance directive**

A person may specify in an advance directive that life-supporting treatment is not desired should they be facing unavoidable death i.e. where there is no outlook for cure, improvement or alleviation but only to a certain prolongation of life. In such cases, doctors must consult the Will Registry to check whether the patient has made an advance directive. If so, it is considered as legally binding.

A person may also or alternatively specify in an advance directive that life-supporting treatment is not desired in case of illness, advanced debilitation due to old age, accidents, heart failure or similar situations that cause such a severe invalidity that they would be permanently unable to take care of themselves physically and mentally. In such cases, doctors must again consult the Will Registry to check whether the patient has made an advance directive. If so, it is considered as advisory.

If a person expresses wishes just before losing capacity which differ from those contained in the advance directive, doctors normally take these wishes into account.

#### 4.3.5 Amending, renewing and cancelling advance directives

An advance directive can be amended or cancelled at any time simply by informing the Will Registry. This can be done by a person with and presumably without capacity (provided that they have sufficient capacity to be able to inform the Will Registry).

## 4.4 Estonia

### 4.4.1 The legal status of advance directives in Estonia

Advance directives are legally binding according to the Law of Obligations. Paragraph 767 of this law which covers the provision of health care services to patients without capacity to exercise their will states:

“(1) If a patient is unconscious or incapable of exercising his or her will for any other reason (a patient without the capacity to exercise his or her will) and if he or she does not have a legal representative or his or her legal representative cannot be reached, the provision of health care services is permitted without the consent of the patient if this is in the interests of the patient and **corresponds to the intentions expressed by him or her earlier** or to his or her presumed intentions and if failure to provide health care services promptly would put the life of the patient at risk or significantly damage his or her health. The intentions expressed earlier by a patient or his or her presumed intentions shall, if possible, be ascertained using the help of his or her immediate family. The immediate family of the patient shall be informed of his or her state of health, the provision of health care services and the associated risks if this is possible in the circumstances.”

### 4.4.2 Conditions surrounding the writing, validity and registering of an advance directive

Capacity is presumed unless proven otherwise. Advance directives are not limited to a set period of time.

#### **4.4.3 What an advance directive can cover**

An advance directive can cover:

- The treatment of medical conditions;
- The treatment of a psychiatric condition;
- Care and welfare decisions;
- Life-supporting treatment;
- Life-saving treatment; and
- Basic care (there is no definition of what this includes but as all care can be refused, it should be possible to refuse basic care).

#### **4.4.4 Obligation to comply with instructions contained in an advance directive**

A doctor cannot be obliged to provide treatment that he/she does not consider to be in the best interests of a patient. However, a doctor can be obliged to discontinue treatment, including life-supporting and life-saving treatment.

The currently expressed wishes of a person with incapacity may take precedence over those expressed in an advance directive provided that the patient is able to reasonably consider the pros and cons of the situation.

#### **4.4.5 Amending, renewing and cancelling advance directives**

An advance directive can be withdrawn by a person with or without capacity. An advance directive can be renewed simply by writing a new one.

#### **4.4.6 Additional comments**

Many doctors are not aware of the law. (Nömper, 2004)

### **4.5 Finland**

#### **4.5.1 The legal status of advance directives in Finland**

Advance directives have legal status in Finland according to regulation 8 of the Act on the Status and Rights of Patients (1992).

Regulation 8 deals with emergency treatment and states that doctors cannot give treatment to a person who is unconscious or unable to express his/her will if such treatment would be against that person's will, as expressed steadfastly and competently at some point in the past.

In 1999, an amendment to regulation 6 of the above-mentioned law made it necessary for legal representatives, next of kin or close friends who are making decisions on behalf of a person with incapacity to take into account their previously expressed wishes.

In Spring 2005, the Act on the Status and Rights of Patients will be amended again. A new regulation (6a) will make it clearer how decisions will be made on behalf of an adult with incapacity. Decisions will be made on the following basis:

1. according to instructions contained in an advance directive (if one has been made, it will always come first);
2. through consultation with a court appointed trustee (a guardian) in health care issues;
3. through consultation with a trustee who has been appointed by the patient to make health care decisions (i.e. a health care proxy);
4. through consultation with a parent, child or close friend or relative.

#### **4.5.2 Conditions surrounding the writing, validity and registering of an advance directive**

A person must have sufficient capacity to make a valid advance directive. Competence is presumed unless proven otherwise. In case of doubt, a doctor should assess a person's capacity.

There is no set procedure for writing or registering advance directives but they should be recorded in the patient's medical file. An advance directive can be made orally (e.g. by a person in hospital) or in writing. If made in writing, it is advisable to have two witnesses. A doctor and/or lawyer may be involved in the process of making an advance directive but this is not necessary.

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

#### **4.5.3 What an advance directive can cover**

An advance directive can cover:

- The treatment of medical conditions;
- The treatment of a psychiatric condition;
- Care and welfare decisions;
- Research;
- Basic care (there is no definition of what this includes but as all care can be refused, it should be possible to refuse basic care);
- Life-supporting treatment;
- Life-saving treatment; and
- The appointment of a health care proxy.

#### **4.5.4 Obligation to comply with instructions contained in an advance directive**

In the case of emergency treatment, advance directives are legally binding. In other cases, they are advisory and it is good medical practice to comply with them.

After an amendment in 2005 to regulation 6 of the Act on the Status and Rights of Patients, doctors will not be obliged to comply with advance directives if it is obvious that the advance directive is based on a person's false perception of their health condition, the nature of the illness or the effectiveness of the treatment methods and medication proposed. Similarly, doctors should not comply with an advance directive if the patient's will concerning treatment and care has changed for the above-mentioned or a similar reason.

If it would be against a doctor's personal beliefs to comply with instructions contained in an advance directive, the doctor must find a colleague who is willing to take over the treatment of the patient.

#### **4.5.5 Amending, renewing and cancelling advance directives**

An advance directive can be amended, renewed or cancelled at any time. This can be done verbally, in writing or through behaviour which clearly indicates this decision. It is not necessary for a person to have full legal capacity (i.e. in every domain) as a greater level of capacity is needed to write an advance directive than to cancel it. This has been discussed in medical circles as well as in literature on jurisprudence.

## **4.6 France**

### **4.6.1 The legal status of advance directives in France**

Advance statements do not have legal status in France. However, the Law of 4 March 2002 relating to Patients' Rights and the Modernisation of the Health Care System gives people the right to appoint in writing a health care proxy.

The health care proxy, known as a "personne de confiance" (trusted person), must be consulted whenever the person is unable to express their wishes or to understand the health care information provided in connection with proposed treatment. The health care proxy also has the right to support the person and be present during medical consultations in order to facilitate decision-making if the latter so desires. The health care proxy could be a relative, friend or doctor.

### **4.6.2 Conditions surrounding the appointment of a health care proxy**

A health care proxy must be appointed in writing and can be cancelled at any time.

When patients are hospitalised, they are systematically asked whether they would like to appoint one. The appointment of a health care proxy in this case is limited to the duration of the hospital stay unless the patient decides otherwise.

The right to appoint a health care proxy does not apply to people who are already under guardianship. If court proceedings are underway to appoint a guardian and a health care proxy has already been appointed, the judge decides whether the health care proxy should maintain or be relieved of his/her duties.

## **4.7 Germany**

### **4.7.1 The legal status of advance directives in Germany**

There is no legally recognised form for advance directives in Germany. However, in current medical practice, it is widely recognised that advance directives reflect a citizen's right to self-determination and are linked to the issue of consent to treatment. Therefore, it is possible for people to refuse or limit specific treatments in advance of their incapacity by means of advance directives.

An advance directive may in certain circumstances be considered as binding e.g. if there is no indication of a change of will related to the specific situation and if the instruction is based on sufficient medical information for the medical treatment proposed. In such cases, a decision that is clearly in favour of withdrawing treatment and is clearly the manifest desire of the patient must be complied with (Council of Europe, 2003).

There is currently a law proposal to add 8 paragraphs on living wills to Book 4 of the Civil Code (BGB) (Family Law, Section 3, Heading 2, Legal guardianship). The proposal also includes an amendment to §1896, par. 1 BGB.

### **4.7.2 Conditions surrounding the writing, validity and registering of an advance directive**

An advance directive can only be written by a person who has capacity and is not subject to external pressure. It is assumed that a person has capacity but confirmation of this by a notary may be helpful. The advance directive should refer to specific treatment or situations and cannot include a request for something that is illegal e.g. assisted suicide. Advice from a doctor is advisable but not necessary.

There is no set procedure for registering advance directives and they are not limited to a set period of time.

### **4.7.3 What an advance directive can cover**

An advance directive can cover:

- The treatment of medical conditions;
- The treatment of a psychiatric condition;
- Care and welfare decisions;
- Research;
- Basic care;

- Life-supporting treatment;
- Life-saving treatment; and
- The appointment of a health care proxy.

In the above-mentioned law proposal on living wills, it is stated that it will not be possible to refuse basic care.

#### **4.7.4 Obligation to comply with instructions contained in an advance directive**

Generally speaking, advance directives in Germany containing decisions about future care are expected to be used by doctors in order to determine the patient's will in case of incapacity. If a doctor treats a patient despite the patient's refusal of such treatment (as expressed in an advance directive), he/she may be charged with physical injury.

Starting, ending and/or continuing any medical intervention can be refused in an advance directive. This includes life-saving and life-supporting treatment. Although there is no clear definition of what the term "basic care" covers, there is currently much debate in Germany amongst members of the medical profession about this issue.

The current wishes of a person with incapacity can in certain circumstances take precedence over those expressed in an advance directive. This tends to be decided on a case-by-case basis.

Doctors who have personal objections to complying with an advance directive must hand over treatment of the patient to a colleague.

#### **4.7.5 Amending, renewing and cancelling advance directives**

An advance directive can be amended, renewed or cancelled at any time. This can be done verbally, in writing or through behaviour which clearly indicates this decision. It is not necessary for a person to have full legal capacity ("volle Geschäftsfähigkeit") in order to withdraw an advance directive.

#### **4.7.6 Additional comments**

It is often difficult for doctors to determine whether instructions/wishes expressed in an advance directive correspond to the current situation. For some, it is also unclear whether failure to initiate or end life-supporting treatment/measures is permitted or, on the contrary, fulfils the criteria for the criminal offence of "murder at the request of the victim" (Mathy and Godschalk, 2004).



## 4.8 Hungary

### 4.8.1 The legal status of advance directives in Hungary

The new Health Act, which was adopted in 1997 (valid in July 1998), states that a patient can prepare a written declaration, an advance directive, to be used in the event of subsequent incapacity.

### 4.8.2 Conditions surrounding the writing, validity and registering of an advance directive

To write an advance directive, a person must have “full disposing capacity”. The advance directive must be in the form of notarial document. In order to be considered valid, a board-certified psychiatrist must have confirmed in a medical opinion, given not more than a month earlier, that the person had made the decision in full awareness of its consequences. If a person is unable to write, the advance directive must be made in the presence of two witnesses who should also sign the document.

### 4.8.3 What an advance directive can cover

In the advance directive, people can refuse specific forms of treatment. Life-supporting or life-saving interventions may be refused if the patient suffers from a serious illness which, according to the current state of medical science, will lead to death within a short period of time even with adequate health care, and is incurable. Certain life-supporting or life-saving interventions may be refused if a person has an incurable disease and as a consequence of the disease is unable to care for him/herself physically or suffers pain that cannot be eased with appropriate therapy.

Concerning organ and tissue donation, it is possible to make an advance directive in order to forbid donation in case of death.

A person can also appoint someone with capacity to consent and/or refuse health care/treatment on his/her behalf in case of subsequent incapacity (i.e. a health care proxy). According to the Health Act, if a person has no legal representative (and presumably no valid advance directive) close relatives can refuse or consent to treatment on their behalf. The Act contains a list describing which people have the right of consent and refusal and in which order. However, it can be stated in the advance directive which of these people should not be given medical information or granted the right to refuse or consent to treatment on their behalf. This can be done irrespective of whether a health care proxy is appointed, and this option is open to minors over 16 also.

It is interesting to note that minors (under the age of 18) are not allowed to refuse treatment, but the appointment of a proxy is allowed for those over 16 years of age.

#### **4.8.4 Obligation to comply with instructions contained in an advance directive**

Doctors are obliged to respect wishes contained in advance directives even if they consider that such wishes are not in the best interests of the patients concerned.

However, for the termination of life-supporting treatment, a refusal may be ignored if there is any doubt concerning the patient's wishes. In section 16 (5) of the Health Act it is stated, "In making decisions on the health care to be provided, the opinion of a patient with no disposing capacity or with limited disposing capacity shall be taken into account to the extent professionally possible..."

Moreover, if there is reason to believe that the correct legal procedure (e.g. concerning the opinion of the board of psychiatrists, the notarial document or the time period to be respected) was not followed, there would be grounds to challenge the advance directive.

The patient's opinion must always be taken into consideration to the greatest possible extent, even if he/she is incapable.

#### **4.8.5 Amending, renewing and cancelling advance directives**

Advance directives must be renewed every 2 years. Only the person who made the advance directive can cancel or amend it. An advance directive may be withdrawn at any time without any formal obligations, even if the patient is not competent. Article 56 of the Hungarian Constitution states, "In the Republic of Hungary, everyone is legally capable." To amend an advance directive, the same formalities apply as for the creation of an advance directive.

#### **4.8.6 Additional comments**

Patients are still not sufficiently aware of the existence of options such as advance directives or the appointment of a health care proxy. Also, advance directives concern only a very narrow range of situations which means that there is no way for patients to escape unnecessary suffering should their disease not be one which leads to death within a short period of time even with full treatment (E. Csernus, 2004).

## **4.9 Ireland**

### **4.9.1 The legal status of advance directives in Ireland**

Advance directives are not legally binding in Ireland. However, according to Costello (1998), in a recent Ward of Court case, certain comments were made by the Supreme Court to the effect that views expressed by a person in relation to future medical treatment (which could have been written in an advance directive) would be taken into account by the Court in coming to decisions in relation to the termination of treatment.

It is possible for a person to complete an Enduring Power of Attorney to sort out their financial affairs and put in place funding arrangements for future care. In addition, a person can give instructions in relation to personal care decisions such as:

- where they should live
- with whom they should live
- whom they should see or not see
- what training or rehabilitation the person should receive
- the person's diet/dress
- who may inspect the person's personal papers
- what housing, social welfare or other benefits the person needs

Nevertheless, a person cannot express wishes regarding treatment that are legally binding.

## **4.10 Italy**

### **4.10.1 The legal status of advance directives in Italy**

There is no legally recognised form for advance directives in Italy. Therefore, anyone can make an advance directive concerning the type of care that they would or would not like to receive in specific situations when they are no longer able to express their wishes. Although the advance directive would be merely advisory, it is possible, according to Law no. 6/2004 to designate a support curator and to write the advance directive for his/her attention and for the attention of the tutelary judge.

### **4.10.2 Conditions surrounding the writing, validity and registering of an advance directive**

The advance directive should refer to specific treatment or situations and cannot include a request for something that is illegal.

To designate a support curator by means of an advance directive, a person must have the necessary capacity to do so. The designation must be made in writing in the form of notarial document. It is in this document that the person can write an advance directive for the attention of the support curator and the tutelary judge.

### **4.10.3 What an advance directive can cover**

The advance directive can cover:

- The treatment of medical conditions;
- Care and welfare decisions;
- Research;
- Basic care;

- Life-supporting treatment;
- Life-saving treatment

## **4.11 Luxembourg**

### **4.11.1 The legal status of advance directives in Luxembourg**

A recently passed law “Loi relative aux soins palliatifs et à l’accompagnement en fin de vie” (Law relating to palliative care and accompaniment at the end-of-life) has given legal status to advance directives.

### **4.11.2 Conditions surrounding the writing, validity and registering of an advance directive**

In order to make an advance directive, a person must be an adult or an “emancipated minor”, have capacity and be a resident of Luxembourg. There is no test of capacity. It is sufficient to be an adult and not subject to a guardianship measure at the time of writing the advance directive. The advance directive must be made in writing and be dated and signed by the person making it.

To register an advance directive, it must be sent by registered mail to the “Direction de la Santé” (Department of Health). The duration of validity of advance directives is not limited to a set period of time.

### **4.11.3 What an advance directive can cover**

An advance directive can cover palliative care and assistance at the end-of-life as well as the refusal of treatment, examinations in view of treatment, life-supporting treatment and life-saving treatment. It cannot be used to cover decisions relating to:

- The treatment of a psychiatric condition;
- Care and welfare decisions;
- Research;
- Basic care;
- The appointment of a health care proxy.

### **4.11.4 Obligation to comply with instructions contained in an advance directive**

Doctors are obliged to comply with refusals expressed in advance directives in the case of incurable and terminal illnesses where the proposed treatment is unlikely to bring either relief or an improvement in the patient’s condition. Doctors are bound to take into account an advance directive but also the evolution of medical knowledge since the advance directive was written. If an advance directive is contrary to the beliefs or values of the doctor in charge of a patient’s treatment and he/she therefore does not want to comply with it, he/she is obliged to transfer the treatment of the patient to a colleague who is willing to do so.

#### 4.11.5 Amending, renewing and cancelling advance directives

An advance directive can be amended, renewed or cancelled at any time by sending a new version or instructions to cancel it to the Department of Health by registered mail. Usually, this can only be done by a person with capacity but according to the Ministry of Health (Mousty, 2004), a doctor could decide whether to comply with a request to cancel an advance directive made by a person lacking capacity. A doctor could also decide whether to respect currently expressed wishes made by a person lacking capacity in cases where they differ from those previously expressed in an advance directive.

### 4.12 Netherlands

#### 4.12.1 The legal status of advance directives in the Netherlands

Article 450 of the Medical Treatment Contracts Act (WGBO) of 1994 contains a paragraph which can be interpreted as referring to advance directives. It is stated therein that if a patient aged 16 or over cannot be deemed capable of reasonably assessing his/her interests with regard to care, the care provider shall comply with the apparent opinion of the patient expressed in writing while he/she was still capable of reasonable assessment.

#### 4.12.2 Conditions surrounding the writing, validity and registering of an advance directive

As stated above, to make a valid advance directive, a person must be aged 16 or over and have the necessary capacity to do so.

#### 4.12.3 What an advance directive can cover

It is not stated what an advance directive can and cannot cover.

#### 4.12.4 Obligation to comply with instructions contained in an advance directive

Care providers are not legally bound by advance directives and may deviate from them if there are good reasons for doing so. In a fact sheet produced by the Ministry of Health, Welfare and Sport (1995), it is stated that care providers are not obliged to search for such statements in emergency situations and that in any case, advance directives must be clear and have been made fairly recently.

The Termination of Life on Request and Assisted Suicide (Review Procedures) Act of 2002 contains provisions on advance directives relating to euthanasia. Such a directive may be regarded as a request for euthanasia by the patient if he/she becomes unable to express his/her will. Physicians are not required to perform euthanasia but those physicians who are willing to do so must regard an advance directive as an expression of the will of the patient (Council of Europe, 2003). However, Wortmann (2004) has suggested that an advance directive cannot be used to request active voluntary euthanasia in the case of patients with dementia as the request must have been expressed continuously and steadfastly by the patient over a long period of time.

#### **4.12.5 Amending, renewing and cancelling advance directives**

Patients may retract or modify an advance directive at any time.

### **4.13 Norway**

#### **4.13.1 The legal status of advance directives in Norway**

Advance directives are not legally binding in Norway. People do nevertheless write them.

In some situations, patients have a right to decide whether treatment that is life-saving, at least in the short run, should be provided or not. According to section 4-9 of the Patients' Rights Act, a patient with serious personal convictions may refuse to receive blood or blood products (e.g. a Jehovah's witness). Similarly, a person may refuse to call off an ongoing hunger strike.

#### **4.13.2 Conditions surrounding the writing, validity and registering of an advance directive**

In Norway, there is an organisation called "mitt livstestamente" which offers help, advice and assistance in filling in advance directive forms. Independent witnesses are required.

#### **4.13.3 What an advance directive can cover**

An advance directive can cover:

- The treatment of medical conditions;
- The treatment of a psychiatric condition;
- Care and welfare decisions;
- Research;
- Life-supporting treatment;
- Life-saving treatment.

It cannot cover the refusal of basic care.

#### **4.13.4 Obligation to comply with instructions contained in an advance directive**

Paragraph 7 of The Health Personnel Act of 1999 deals with the question of emergency health care. It states: Health personnel shall immediately provide the health care they are capable of when it must be assumed that the health care is of vital importance. Pursuant to the limitations laid down by the Patients' Rights Act § 4-9, necessary health care shall be given, even if the patient is incapable of granting his consent thereto, and even if the patient objects to the treatment.

However, § 4-9 of the Patients' Rights Act states that a dying patient is entitled to object to life-supporting treatment. If a dying patient is incapable of communicating their wishes concerning treatment, the health care personnel may withdraw

health care provided that the patient's next of kin so requests and that the health care personnel, based on an independent evaluation, find that this also corresponds with the patient's wishes. Presumably, such wishes could be recorded in an advance directive.

Health care personnel must ensure that a patient is of age, that he/she has been given adequate information and that he/she has understood the possible consequences on their own health of refusing treatment.

#### **4.13.5 Amending, renewing and cancelling advance directives**

An advance directive may be withdrawn or amended at any time by a person with capacity.

## **4.14 Spain**

### **4.14.1 The legal status of advance directives in Spain**

Advance directives have been legal in Spain since 14 November 2002. The Basic Law 41/2002 regulating the Autonomy of the Patient and Rights and Duties related to Clinical Information and Documentation is applicable throughout the whole of Spain. It permits people to state their wishes with regard to medical treatment whilst they still have the capacity to do so.

### **4.14.2 Conditions surrounding the writing, validity and registering of an advance directive**

In order to write a valid advance directive, a person must be at least 18 years of age, free from pressure and have the necessary capacity to do so.

In Spain, everyone is presumed to have capacity unless proven otherwise. Therefore, unless a person has been declared legally incompetent, they can write an advance directive. If the document is signed in the presence of a notary, the notary has to confirm that the person has the necessary capacity to sign such a document. However, it is not necessary to involve a notary.

In most of the autonomous communities advance directives are made either in the presence of a notary or privately with three witnesses. These witnesses should be named and also sign the advance directive. It is presumed that by signing the document they are also confirming that the person writing the advance directive has the capacity to do so. Two out of the three witnesses must not be family members or have any economic/business relationship with the person making the advance directive. In some autonomous communities, where very few advance directives are made, it is possible to just sign the document in front of a health care professional or the person who is in charge of the advance directives registry.

Several autonomous regions have advance directive registries, so people writing advance directives must ensure that they follow the formal procedure of the region in

which they reside. Legislation is pending to create a national register for advance directives.

Other conditions governing the validity of advance directives include the following:

- The instructions contained in the advance directive should not be against the law;
- The instructions contained in the advance directive should not be contrary to “lex artis” or good medical practice;
- The circumstances must correspond to those previously envisaged.

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

#### **4.14.3 What an advance directive can cover**

The Basic Law 41/2002 does not specify what an advance directive can or cannot cover. It can therefore be presumed that it could cover:

- The treatment of medical conditions;
- The treatment of a psychiatric condition;
- Care and welfare decisions;
- Research;
- Basic care;
- Life-supporting treatment;
- Life-saving treatment.

It can also be presumed that advance directives could cover the appointment of a health care proxy, information about a person’s beliefs, philosophy of life or ethical principles, values, situations in which the instructions should be taken into account, organ donation etc. (Rovira, 2004)

#### **4.14.4 Obligation to comply with instructions contained in an advance directive**

With regard to the refusal of life-supporting and life-saving treatment, some lawyers point out that doctors are faced with the conflicting duty of complying with the patient’s request and fulfilling their own obligation to preserve life and maintain health. Nevertheless, the law states that doctors can only ignore instructions contained in an advance directive if the instructions are against the law, contrary to good medical practice or do not correspond to the situation previously envisaged. If a doctor fails to comply with instructions contained in an advance directive and cannot justify the decision on the basis of the three above-mentioned conditions, he/she must state why the patient’s instructions were ignored.



#### 4.14.5 Amending, renewing and cancelling advance directives

Advance directives can be amended, renewed or cancelled at any time provided that the person has the necessary capacity to do so. This must be done in writing. Some people involve a notary or the organisation EXIT. It is unlikely that a person lacking capacity would be allowed to withdraw an advance directive. If several advance directives have been made, the last one will be considered valid and any previous ones considered invalid.

### 4.15 Switzerland

#### 4.15.1 The legal status of advance directives in Switzerland

There is currently no specific legislation relating to advance directives at federal level in Switzerland. However, in a few cantons (e.g. Aargau, Appenzell, Ausser-rhoden, Genf, Lucerne, Wallis and Zurich), advance directives are covered by health care legislation. For example, in the Health Law of 1996 of the canton of Vallais, article 20 states:

- 1) Everyone can make an advance directive concerning the type of care that they would or would not like to receive in specific situations when they are no longer able to express their wishes.
- 2) In the same way, everyone can designate a person who will be responsible for making decisions on their behalf concerning the choice of care to be provided in these same circumstances.

If such a law exists, then advance directives must be respected. Otherwise, there tends to be a lack of legal clarity although in “doctrine” and according to jurisprudence the general opinion is that they should be respected as long as they correspond to the current situation and there is no indication that the patient’s will has changed.

Advance directives are also governed by laws related to the protection of privacy and personal liberty (article 27 of the Swiss civil code and article 10 of the constitution). However, there are different legal organisations in each canton which are responsible for the enforcement of these laws.

In the foreseeable future, there will be a reform (at federal level) of the guardianship law which will be known as the “Erwachsenenschutzrecht”.

Article 370 of this law proposal allows for a competent adult to appoint in writing one or more people who in the event of his/her incapacity can consent to medical treatment on his/her behalf (i.e. a health care proxy).

The law proposal also deals with advance directives. Article 373 states that a person can write an advance directive covering the acceptance or refusal of medical treatment.

#### **4.15.2 Conditions surrounding the writing, validity and registering of an advance directive**

There is no time limit on the duration of advance directives. However, in the reform on guardianship, it is proposed that the appointment of a health care proxy should only be valid if the person who made the appointment loses capacity within 10 years. It is also planned in the reform that the appointment of a health care proxy should be publicly certified and the document deposited at an official organisation.

With regard to advance directives, it is specified in the law proposal that an advance directive must be sufficiently precise, correspond to the author's presumed wishes and be an expression of the author's free will.

It is not necessary to have witnesses or to involve officials when writing an advance directive. The document must, however, be in writing or print and must be signed. Several organisations (e.g. the Swiss Patients Organisation) have ready-made advance directives that people can use.

Capacity is presumed but in case of doubt, experts are called in to try to determine whether the author of the advance directive had the necessary capacity at the time the document was produced.

#### **4.15.3 What an advance directive can cover**

There are no conditions regarding the content of advance directives. They cannot, however, contain wishes or instructions that are against the law e.g. for active euthanasia. Consent or refusal of life-supporting and/or life-saving treatment is possible.

#### **4.15.4 Obligation to comply with instructions contained in an advance directive**

It is generally accepted that doctors should comply with instructions/wishes contained in an advance directive provided that the conditions for making a valid advance directive have been fulfilled. In case of doubt, relatives should be consulted and, if need be, an ethics committee and guardianship officials. Such provisions can be found in certain cantonal laws.

Doctors are not obliged to comply with an advance directive if there are grounds to believe that the document no longer corresponds to the patient's wishes. This is difficult to determine once a person has lost capacity. However, in the law of the canton of Aargau, in case of doubt doctors are expected to decide in favour of the suspected will and interests of the patient.

#### **4.15.5 Amending, renewing and cancelling advance directives**

An advance directive can be amended, renewed or cancelled at any time.

## 4.16 United Kingdom (England and Wales)

### 4.16.1 The legal status of advance directives in England and Wales

Until recently, no one was legally authorised to consent or refuse particular medical treatment on behalf of an adult lacking capacity and there was no statute directly governing the use of advance directives in the United Kingdom. Advance directives had legal status in England and Wales under Common Law but an advance directive concerning a person's treatment for mental disorder would not be legally binding if the person who made it was subject to compulsory powers under the Mental Health Act 1983. However, an advance directive concerning a physical disorder unrelated to the mental disorder would not be affected by a person's detention under the Mental Health Act.

In April 2005, the Mental Capacity Bill received Royal Assent and became the Mental Capacity Act 2005. It provides a statutory framework in England and Wales for people who may not be able to make their own decisions due to a mental health problem, a learning disability or an illness such as dementia. Sections 24 to 26 deal with advance decisions to refuse treatment. Other decisions are presumably covered by common law provisions governing consent to treatment.

### 4.16.2 Conditions surrounding the writing, validity and registering of an advance directive

A person must be over 18 and have sufficient capacity to make an advance directive. This means that a person may lack capacity in one domain (e.g. to make financial decisions), but still be considered capable of writing an advance directive. Capacity is presumed but in case of doubt, it can be established by a court of law. Although advance directives are usually written documents, they may also be witnessed by oral statements, signed printed cards or discussion notes recorded in patients' medical files. Advance directives do not need to be witnessed by a solicitor and there is no registration procedure.

In England and Wales, people under the age of 18 can make advance directives but they are not legally binding.

With specific reference to advance directives containing decisions to refuse treatment, the Mental Capacity Act 2005 has the following conditions (§25):

- (1) An advance decision does not affect the liability which a person may incur for carrying out or continuing a treatment in relation to P (the person who made the advance directive) unless the decision is at the material time (a) valid, and (b) applicable to the treatment.
- (2) An advance decision is not valid if P
  - a) has withdrawn the decision at a time when he or she had capacity to do so,

- b) has, under a lasting power of attorney created after the advance decision was made, conferred authority on the donee (or, if more than one, any of them) to give or refuse consent to the treatment to which the advance decision relates, or
  - c) has done anything else clearly inconsistent with the advance decision remaining his/her fixed decision.
- (3) An advance decision is not applicable to the treatment in question if at the material time P has capacity to give or refuse consent to it.
- (4) An advance decision is not applicable to the treatment in question if
- a) that treatment is not the treatment specified in the advance decision,
  - b) any circumstances specified in the advance decision are absent, or
  - c) there are reasonable grounds for believing that circumstances exist which P did not anticipate at the time of the advance decision and which would have affected his/her decision had he/she anticipated them.
- (5) An advance decision is not applicable to life-sustaining treatment unless
- a) the decision is verified by a statement by P to the effect that it is to apply to that treatment even if life is at risk, and
  - b) the decision and statement comply with subsection (6).
- (6) A decision or statement complies with this subsection only if
- a) it is in writing,
  - b) it is signed by P or by another person in P's presence and by P's direction,
  - c) the signature is made or acknowledged by P in the presence of a witness, and
  - d) the witness signs it, or acknowledges his/her signature, in P's presence.
- (7) The existence of any lasting power of attorney other than one of a description mentioned in subsection (2)(b) does not prevent the advance decision from being regarded as valid and applicable.

#### **4.16.3 What an advance directive can cover**

Advance directives can include decisions relating to:

- Treatment of medical conditions;
- Treatment of psychiatric conditions;
- Care and welfare decisions;
- Life-supporting treatment;
- Life-saving treatment;

- Appointment of a health care proxy and
- Research

but not the refusal of basic care (procedures essential to keep the person comfortable, e.g. warmth, shelter, pain relief and the management of distressing symptoms), the offer of food and drink by mouth or requests for euthanasia or unreasonable treatment.

#### **4.16.4 Obligation to comply with instructions contained in an advance directive**

To be considered legally binding, an advance directive must be clear, unambiguous and reasonably proximate. Doctors have a legal and ethical obligation to act in the best interests of patients which in addition to clinical factors involves taking into account the past and present wishes of patients. Advance directives are binding only when they concern the refusal of treatment. General statements or preferences should be taken into account and respected if appropriate but they are not legally binding. Section 4 (6) of the Mental Capacity Act states that in determining what is in a person's best interests, the person making the determination "must consider, so far as is reasonably ascertainable:

- The person's past and present wishes and feelings (and in particular, any relevant written statement made by him or her when he/she had the capacity);
- The beliefs and values that would be likely to influence his/her decision if he/she had capacity;
- The other factors that he/she would be likely to consider if he/she were able to do so."

In all cases, a contemporaneous decision by a competent person overrides any decision made in an advance directive. As competence is not an all-or-none affair, it should also be possible to challenge or express disagreement with a particular decision recorded in an advance directive provided that the person has sufficient capacity with regard to that decision. Doctors should comply with advance directives even if they go against their personal beliefs or values. They may arrange for a colleague to take over a patient's treatment but if this is not possible, they must comply with a valid advance directive.

Concerning advance decisions to refuse treatment, the Mental Capacity Act (section 26, §5) states "Nothing in an apparent advance decision stops a person – (a) providing life-sustaining treatment, or (b) doing any act he/she reasonably believes to be necessary to prevent a serious deterioration in P's condition, while a decision as regards to any relevant issue is sought from the court."

#### **4.16.5 Amending, renewing and cancelling advance directives**

An advance directive can be amended or cancelled at any time provided that a person has the capacity to do so. A withdrawal, partial withdrawal or alteration of an advance decision to refuse treatment need not be in writing unless it refers to life-sustaining treatment (Mental Capacity Act, Section 24, §§4-5).

## **4.17 United Kingdom (Scotland)**

### **4.17.1 The legal status of advance directives in Scotland**

There is no statute directly governing the use of advance directives in the United Kingdom. However, the Department of Health's Reference Guide to Consent for Examination or Treatment (2001) contains the following section on advance refusals of treatment which provides more precision:

“While professionals cannot be required by such directives to provide particular treatments (which might be inappropriate), case law is now clear that an advance refusal of treatment which is valid and applicable to subsequent circumstances in which the patient lacks capacity is legally binding. An advance directive is valid if made voluntarily by an appropriately informed person with capacity. Failure to respect such an advance refusal can result in legal action against the practitioner.”

The Adults with Incapacity (Scotland) Act 2000 is the main legislation on proxy decision making for adults with incapacity in Scotland but it makes no reference to advance directives. It covers financial decisions (except wills) and welfare decisions, which include all health care, except compulsory treatment for mental disorder under the Mental Health (Scotland) Act 1984. In the Adults with Incapacity (Scotland) Act 2000, an advance refusal does not seem to have a direct effect. Rather, a person needs to ensure that his/her guardian/welfare attorney is aware of his/her wishes and it is the refusal of the guardian/welfare attorney of the treatment in question that is binding – subject to appeals procedures etc.

### **4.17.2 Conditions surrounding the writing, validity and registering of an advance directive**

A person must be over 18 and have sufficient capacity to make an advance directive. This means that a person may lack capacity in one domain (e.g. to make financial decisions), but still be considered capable of writing an advance directive. Capacity is presumed but in case of doubt, it can be established by a court of law. Although advance directives are usually written documents, they may also be witnessed by oral statements, signed printed cards or discussion notes recorded in patients' medical files. They must be witnessed by a solicitor and registered with the office of the Public Guardian.

In Scotland, to appoint a health care proxy (i.e. a welfare attorney), a person must be aged 16 or over and must obtain a certificate from a solicitor confirming that he/she understands what is involved and is not acting under undue influence.

#### 4.17.3 What an advance directive can cover

Advance directives can include decisions relating to:

- Treatment of medical conditions;
- Treatment of psychiatric conditions;
- Care and welfare decisions;
- Life-supporting treatment;
- Life-saving treatment;
- Appointment of a health care proxy;
- Research.

but not the refusal of basic care (procedures essential to keep the person comfortable, e.g. warmth, shelter, pain relief and the management of distressing symptoms), the offer of food and drink by mouth or requests for euthanasia or unreasonable treatment.

According to the Adults with Incapacity (Scotland) Act 2000, health care proxies must be consulted about treatment decisions unless it is impracticable or unreasonable to do so.

#### 4.17.4 Obligation to comply with instructions contained in an advance directive

To be considered legally binding, an advance directive must be clear, unambiguous and reasonably proximate. Doctors have a legal and ethical obligation to act in the best interests of patients which, in addition to clinical factors, involves taking into account the past and present wishes of patients. Advance directives are binding only when they concern the refusal of treatment. General statements or preferences should be taken into account and respected if appropriate but they are not legally binding.

In all cases, a contemporaneous decision by a competent person overrides any decision made in an advance directive. As competence is not an all-or-none affair, it should also be possible to challenge or express disagreement with a particular decision recorded in an advance directive provided that the person has sufficient capacity with regard to that decision.

Section 1 of the Adults with Incapacity (Scotland) Act 2000 provides five Principles, which must be followed by those who intervene in the finances or welfare of an adult with incapacity under the terms of the Act. The third Principle requires that anyone intervening must take into account the 'past and present wishes and feelings' of the adult as far as these are ascertainable. The final decision on what action to take rests with the person given responsibility for the intervention under the Act. This may be an attorney appointed by the adult when capable, a doctor authorised to give medical treatment, a researcher, an intervener or a guardian.

Doctors should comply with advance directives even if they go against their personal beliefs or values. They may arrange for a colleague to take over a patient's treatment but if this is not possible, they must comply with a valid advance directive.

#### **4.17.5 Amending, renewing and cancelling advance directives**

An advance directive can be amended or cancelled at any time provided that a person has the capacity to do so. Annex 1: Advance directives in International and European conventions.







*Advance directives  
in International  
Conventions*

## **5** *Advance directives in International Conventions*

### **5.1 WHO Declaration on the promotion of patients' rights in Europe**

Article 3.3.:

“When a patient is unable to express his or her will and a medical intervention is urgently needed, the consent of the patient may be presumed, unless it is obvious from a previously declared expression of will that consent would be refused in the situation.”

### **5.2 European Convention on Human Rights and Biomedicine**

Article 9:

“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.”

### **5.3 Council of Europe Recommendation on principles concerning the legal protection of incapable adults**

Principle 9.:

“In establishing or implementing a measure of protection for incapable adults, the past and present wishes and feelings of the adults should be ascertained so far as possible, and should be taken into account and given due respect.

This principle implies, in particular, that the wishes of the adult as to the choice of any person to represent or assist him or her should be taken into account and, as far as possible, given due respect.”



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**Alzheimer Europe Report**



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