



Alzheimer Europe position on the disclosure of the diagnosis to people with dementia and carers

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I. Executive Summary

The purpose of this document is to present Alzheimer Europe's position on the disclosure of the diagnosis of dementia to people with dementia and their carers. This position is based on work carried out in the framework of the Lawnet project (1998)¹, which led to the drafting of recommendations on how to improve the legal rights and protection of people with incapacity, a survey² carried out by Alzheimer Europe involving over 1,000 carers of people with Alzheimer's disease (in Scotland, Poland, France, Germany and Spain) and recent research.

1. People with dementia have the right to be informed of their diagnosis.
2. Whilst care should be taken to avoid causing unnecessary anxiety and suffering, information about the diagnosis should not be withheld solely on the grounds that a person has dementia, memory problems and/or communication difficulties.
3. Additional information should be provided when the diagnosis is disclosed about the person's general state of health, prognosis, treatment possibilities, potential risks and side-effects linked to anti-dementia drugs, psychosocial and non-pharmacological approaches to managing symptoms and cognitive decline, the availability of services to which the person is entitled and the name of the doctor who will have overall responsibility for the person's ongoing care/treatment.
4. Written information should always be provided as a back-up.
5. People with dementia may have difficulty taking in all the information provided at the time of diagnosis. For this reason, it should be possible for them to have a second meeting with their doctor at a later date in order to obtain further information/clarification concerning the diagnosis. They should also have access to other forms of post-diagnostic support.
6. Every person diagnosed with dementia should be provided with the contact details of the national and local Alzheimer associations at the time of diagnosis, along with information about the kinds of services that the associations offer.
7. A system should be devised in order to ensure that all relevant medical professionals receive appropriate and up-to-date information about Alzheimer associations. It may be necessary to work in close collaboration with the State and/or professional medical bodies/associations in order to achieve this goal.
8. Attempts should be made to provide comprehensive information in such a way as to maximise the ability of the person with dementia to understand. Attention should be paid to any possible difficulty understanding, retaining information and communicating, as well as the person's level of education, reasoning capacity, current understanding of dementia and cultural background.
9. Medical professionals should be kept updated on recent developments in the treatment of dementia and receive training in the disclosure of the diagnosis/breaking bad news.
10. The next of kin, partner and potential carers of the person with dementia should be informed of the diagnosis of dementia if they so request, provided that the person with

¹ For further details, please refer to the "legal rights" section on our website: <http://www.alzheimer-europe.org/?lm1=51F10147EA26>

² Alzheimer Europe (2006), Who cares? The state of dementia care in Europe

dementia agrees to this and does not, or did not previously, request that they should not be informed. In fact, health care professionals should encourage people with dementia to involve relatives and close friends in the disclosure procedure.

11. Nevertheless, a clear refusal by the person with dementia to disclose the diagnosis to any third party should be respected regardless of the extent of incapacity, unless it is clear that this would not be in the best interests of the person with dementia.
12. Disclosure in such cases should be done on a need to know basis i.e. to enable those concerned to care effectively for the person with dementia.
13. People who are informed of someone else's diagnosis of dementia in connection with their work (either voluntary or paid) should be obliged to treat such information with confidentiality.
14. Medical professionals should not disclose the diagnosis to close relatives, friends and/or carers of the person with dementia as a means to avoid personal responsibility for disclosure of the diagnosis to the person with dementia.
15. Medical professionals who do not disclose the diagnosis of dementia to the patient concerned should be obliged to record this in the medical file of the person with dementia, along with a justification for this decision.
16. People with dementia have the right to request not to be informed of their diagnosis.
17. People with dementia have the right to choose who (if anyone) should be informed of the diagnosis on their behalf.
18. People with dementia have the right to request a second opinion.
19. The above-mentioned rights relating to the disclosure (or non-disclosure) of the diagnosis of dementia should be covered by national legislation.

II. Background

The following section provides background information on the disclosure of the diagnosis to people with dementia and their carers. The main issues covered include the right to a diagnosis, who should be informed, how the diagnosis should be disclosed, the kind of information that should be provided at the time of diagnosis and the role that Alzheimer associations should play in the overall process.

II.1 Do people with dementia want to be informed of their diagnosis?

Several studies confirm that people with dementia prefer to be informed of the diagnosis of dementia (Marzanski, 2000; Jha et al., 2001; Clare, 2003; Dautzenberg et al., 2003; Van Hout et al. 2006). Bamford et al. (2004) found that non-disclosure or vagueness was reported by people with dementia as being confusing or upsetting. Other studies also confirm that most people with suspected dementia want to be informed of the diagnosis and are distressed if not provided with adequate information (Clare, 2003; Pratt and Wilkinson, 2003). Jha et al. (2001) found that even people with severe dementia want to know the diagnosis. On the other hand, it should be borne in mind that some people do not want to know what is wrong with them and state this very clearly (Marzanski, 2000).

Derksen et al. (2006) interviewed 18 pairs of people with dementia and their partners in the Netherlands. They found that those who already suspected dementia (mostly due to personal experience within their families) were relieved by the diagnosis even though they had hoped for another explanation for the cognitive problems experienced. Those who had no suspicions of

dementia tended to react to the diagnosis with shock. Keightley and Mitchell (2004) describe some of the pros and cons of disclosure as follows:

“Although by being truthful you may confirm someone’s worst fears, you also give them the opportunity to come to terms with the situation and work through their feelings. Without a diagnostic framework within which to understand their experience many people with dementia will be left frightened that they are going mad with little or no support.”

II.2 What are the advantages of disclosing a diagnosis to people with dementia?

Disclosure of the diagnosis and the provision of information related to a person’s state of health are basic rights (please see section on legal rights) which should be respected, provided that this is what the person with dementia wants. Knowledge of the diagnosis may, amongst other things, also give the person with dementia the possibility to:

- confirm suspicions and put an end to uncertainty
- gain a better understanding of problems
- come to terms with personal changes and losses caused by the disease
- obtain information about the progression of the disease, treatment, care and services
- develop positive coping strategies and short-term goals
- give informed consent for anti-dementia drugs and/or to participate in clinical trials
- make decisions about future care preferences
- write an advance directive
- sort out personal finances and take decisions regarding property and assets

However, as most of the above-mentioned possibilities require a certain degree of mental capacity, it is not only important to inform people with dementia of their diagnosis but also to inform them at a sufficiently early stage of the disease to enable them to make decisions about their present and future lives.

Some of the advantages of being informed of the diagnosis are linked to a person’s entourage and may only become evident a few weeks or months later. Vernooij-Dassen et al. (2006) examined the impact of receiving a diagnosis at 2 and 12 weeks after disclosure. They found that sharing the diagnosis with family and friends often brought positive responses. In many cases, people were surprised at what others already knew. Being aware of the diagnosis may enable people with dementia and their carers to gradually deal with issues related to autonomy, to come to terms with changes in their relationships and to benefit from the support of friends and relatives.

II.3 Do carers think that people with dementia should be informed of their diagnosis?

Despite the potential advantages linked to disclosure of the diagnosis and even though a high percentage of elderly people state that they would like to know a hypothetical diagnosis of dementia, carers are often opposed to informing people with dementia of the diagnosis (Van Hout et al., 2006). A review of several studies found that there were differences between countries. In Ireland and Italy, for example, carers were found to be more reluctant to share the diagnosis with the person with dementia (17% and 40% respectively) than in England and the Netherlands (84% and 100% respectively) (Van Hout et al., 2006).

Maquire et al. (1996) found that whilst only 17% of Irish carers thought that the person with dementia should be informed of the diagnosis, 71% would want to be informed if they developed Alzheimer’s disease themselves. The authors suggest that this inconsistency might reflect “a generational difference in the perception of the disease, a paternalistic desire by family members to protect patients from the harsh reality of their condition, or a reluctance of relatives to deal with the patient’s knowledge and possible grief.”

II.4 What is the attitude within the medical profession towards disclosure of the diagnosis?

There is a growing consensus within the medical profession that the diagnosis should be disclosed to the person with dementia, but unfortunately, this is not yet standard practice. In 1996, Maguire et al. likened the tendency of doctors to withhold the diagnosis from the person with dementia to the situation regarding the disclosure of diagnoses of cancer in the past (whereby 90% of doctors expressed a preference not to tell cancer patients their diagnosis in 1961, changing to 97% in favour of disclosure by 1977).

Nevertheless, in 1997, a survey carried out in Scotland revealed that less than 50% of psychiatrists disclosed the diagnosis to the person with dementia (Clafferty, 1998). A separate survey revealed that only 5% of general practitioners always told the patient the diagnosis of dementia, with a further 34% often doing so (Vassilas and Donaldson, 1998). A small-scale study by Keightley and Mitchell (2004) looked into the possible reasons for such reticence. They found that the main factors influencing disclosure practice were uncertainty as to whether the person with dementia would really want to know and fear that telling them would cause harm. Similarly, on the basis of an analysis of numerous studies, Bamberg (2004) found that opposition towards disclosure was often based on perceived negative consequences such as the fear of upsetting the person with dementia, increasing disability, negative effects on self-esteem, hyper-vigilance and the potential for precipitating a crisis. However, according to Jha et al. (2001), claims that disclosing the diagnosis does damage, e.g. by causing stigmatisation, depression and/or suicidal ideation, are not based on empirical evidence.

Some doctors are concerned about the uncertainty of the diagnosis and feel that they have nothing to offer i.e. in terms of treatment and care (Van Hout et al., 2000; Cantegreil-Kallen et al., 2005; Vernooij-Dassen, Moniz-Cook et al., 2005). In Keightley and Mitchell's study (2004), medical professionals expressed a strong sense of both hopelessness and helplessness when confronted with dementia. It is therefore important that doctors and other medical professionals are aware of existing drugs for Alzheimer's disease, receive training in breaking bad news and can provide the contact details of an Alzheimer association when a diagnosis is disclosed. They should also be aware of psychosocial interventions aimed at people with dementia and their families, which can significantly reduce the progression of cognitive decline and may also help people with dementia and carers to deal with their own feelings of helplessness (Moniz-Cook et al., 1998).

II.5 Should carers³ be informed of the diagnosis?

A person with dementia is entitled to receive the diagnosis in private. However, many people with dementia are accompanied by carers when they go to the doctor's. Consequently, carers are often informed of the diagnosis at the same time as the person with dementia. This has the advantage that the carer may be better able to understand and remember what is said. It may also be helpful for the person with dementia to be with a trusted person when receiving such a diagnosis, particularly as they may experience strong emotions. Another advantage is that knowing the diagnosis may enable carers to seek information, advice and services to help them cope with the task of caring.

On the other hand, people with dementia might prefer not to inform carers and/or relatives about their diagnosis. It is therefore essential to ensure that the person with dementia agrees to the diagnosis being disclosed to other people. A clear refusal (including a previous request) by the person with dementia to grant access to information to any third party should be respected

³ In this context, the carer is used to refer to a relative, close friend or other person who has close and regular contact with the person with dementia which involves or will later involve providing informal care.

regardless of the extent of incapacity, unless it is clear that this would not be in their best interests. They should not be under any obligation to justify this decision.

The practice of disclosing the diagnosis to carers and not to people with dementia is quite common (van Hout et al., 2006). This does not respect the right of the person with dementia to be informed and/or their right to confidentiality. Furthermore, it places a potential burden on carers to disclose the diagnosis to the person with dementia themselves even though they are unlikely to be equipped with the necessary information and understanding of the disease to be able to carry out this task effectively, and might not even be in favour of sharing the diagnosis. Clearly, medical professionals should not inform carers of the diagnosis simply to avoid responsibility for disclosure of the diagnosis to the person with dementia.

Marzanski (2000) interviewed 30 people with dementia. The majority stated that they would prefer to receive information about their disease from a doctor. Very few said that they would prefer to receive information from other people such as relatives or anyone with adequate knowledge.

To summarise, carers should be informed of the diagnosis on a need to know basis, provided that the person with dementia has not expressed an objection to their being informed.

II.6 What is the legal situation with regard to the disclosure of the diagnosis?

Legislation is changing. In the past, patients' rights were often protected solely by codes of medical deontology (particularly in the southern countries such as France, Italy, Portugal, Spain and Greece), which placed medical practitioners under the obligation to inform patients of their state of health. However, many included a paragraph which freed them from this obligation if there was reason to believe that such disclosure would not be in the best interests of the patient. For example, in the Portuguese Code of Medical Ethics of 1985 (article 40), it is stated that:

“Prognoses and diagnoses shall be revealed to the patient, unless the physician, for reasons which his/her conscience tells him/her are important, feels that they should not be revealed. A prognosis of fatal illness may, however, only be revealed to the patient subject to the precautions dictated by a thorough knowledge of his/her temperament, specific health conditions and character; but as a rule it should be revealed to the nearest of kin considered by the physician as suitable, unless the patient has previously forbidden this or has indicated other persons to whom the information should be divulged.”

This could be considered as a rather paternalistic approach. Recent legislation (dating from 1992 to 2005) in Bulgaria, Cyprus, Denmark, Finland, Hungary, Iceland, Latvia, Lithuania, the Netherlands and Norway places the emphasis on patients' rights rather than doctors' obligations – although the two are obviously linked. In some cases (e.g. in Spain and Greece), a code of medical ethics exists alongside a law containing a section on patients' rights. In Luxembourg and France, the codes of medical deontology are legislative acts.

The following extract from the Finnish Act on the Status and Rights of Patients (1992)⁴ provides an example of legislation relating to the right to be informed of one's state of health.

"A patient shall be given information about his/her state of health, the significance of the treatment, various alternative forms of treatment and their effects and about other factors related to his/her treatment that are significant when decisions are made on the treatment given to him/her.

However, this information shall not be given against the will of the patient or when it is obvious that giving the information would cause serious hazard to the life or health of the patient.

Health care professionals should try to give the information in such a way that the patient can understand it. If the health care professional does not know the language used by the

⁴ Act on the Status and Rights of Patients No. 785/92 of 17 August 1992

patient or if the patient because of a sensory handicap or speech defect cannot be understood, interpretation should be provided if possible."

A few countries⁵ have introduced the concept of healthcare proxies and/or trusted representatives into their healthcare legislation. These proxies and representatives act as representatives of the patients and may be consulted when healthcare decisions are being made. They would therefore need to have access to information on the patient's state of health in order to make informed decisions.

II.7 Are there any relevant European codes or recommendations?

In addition to laws and codes of medical ethics, there is a European recommendation on patients' rights, which contains a few relevant articles.

In 1994, the European Consultation on the Rights of Patients was held in Amsterdam under the auspices of the WHO Regional Office for Europe (WHO/EURO), and hosted by the Government of the Netherlands. The purpose of this consultation was to define principles and strategies for promoting the rights of patients, within the context of the health care reform process underway in most countries. The consultation led to the endorsement of the *Principles of the Rights of Patients in Europe: A Common Framework*. Whilst this is not a law, several of its articles on the right to information are nevertheless reflected in current national laws relating to patients' rights in Europe. The relevant articles are as follows:

2.2 Patients have the right to be fully informed about their health status, including the medical facts about their condition; about the proposed medical procedures, together with the potential risks and benefits of each procedure; about alternatives to the proposed procedures, including the effect of non-treatment; and about the diagnosis, prognosis and progress of treatment.

2.3 Information may only be withheld from patients exceptionally when there is good reason to believe that this information would without any expectation of obvious positive effects cause them serious harm.

2.4 Information must be communicated to the patient in a way appropriate to the latter's capacity for understanding, minimizing the use of unfamiliar technical terminology. If the patient does not speak the common language, some form of interpreting should be available.

2.5 Patients have the right not to be informed, at their explicit request.

2.6 Patients have the right to choose who, if anyone should be informed on their behalf.

2.7 Patients should have the possibility of obtaining a second opinion.

2.8 (concerns rules and routines in health care establishments)

2.9 Patients should be able to request and be given a written summary of their diagnosis, treatment and care on discharge from a health care establishment.

This was followed by the Council of Europe's Convention on Human Rights and Biomedicine in 1997⁶, which contained the following article on "private life and right to information".

Article 10 - Private life and right to information

⁵ Belgium, Finland, France, Germany, Georgia, Hungary and Scotland (known as a Welfare Power of Attorney in Scotland)

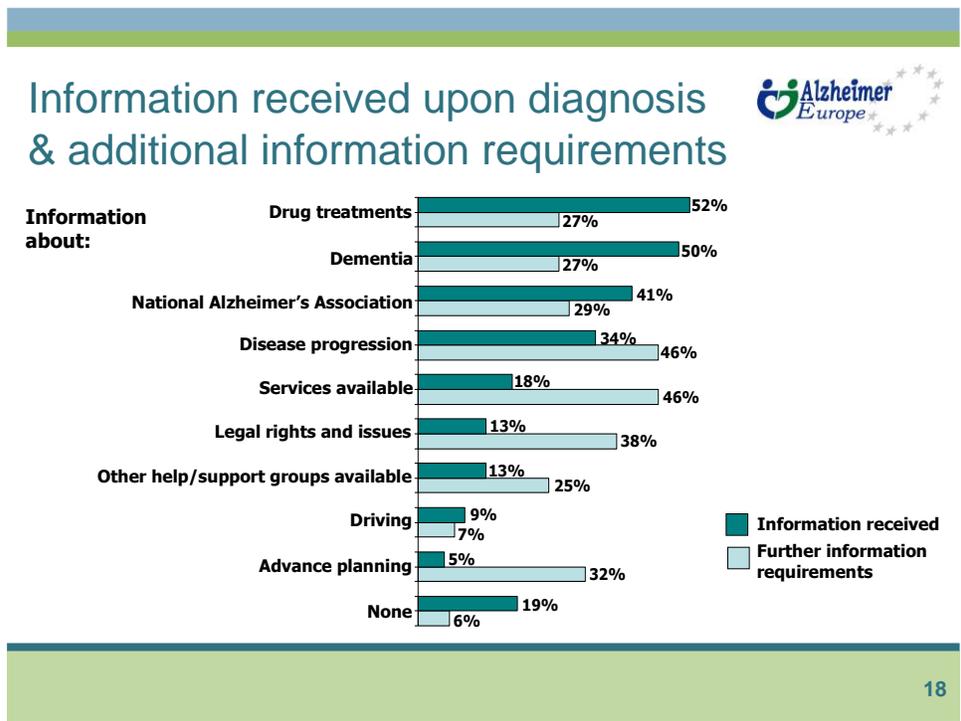
⁶ Council of Europe (1997), Convention on human rights and biomedicine (Done at Oviedo, Spain, April 4, 1997)

- 1 Everyone has the right to respect for private life in relation to information about his or her health.
- 2 Everyone is entitled to know any information collected about his or her health. However, the wishes of individuals not to be so informed shall be observed.
- 3 In exceptional cases, restrictions may be placed by law on the exercise of the rights contained in paragraph 2 in the interests of the patient.

II.8 What kind of information do carers and people with dementia want and receive when the diagnosis is disclosed?

When a person is informed of the diagnosis of dementia, they should also be provided with an explanation of what dementia is and information about their general state of health, prognosis, treatment possibilities, potential risks and consequences of treatment, side-effects and the availability of services.

In the framework of the “Who Cares?” study mentioned earlier, carers were asked what kind of information they were given at diagnosis and what kind of additional information they would have liked. The following responses were received from the 1,181 carers involved in the study (in France, Germany, Scotland, Spain and Poland).



As can be seen from the above table, only 50% of carers were given information about dementia and 52% about anti-dementia drugs. Very few were informed about services and other forms of support available (18% and 13% respectively). 46% wanted to have more information about the progression of the disease and available services.

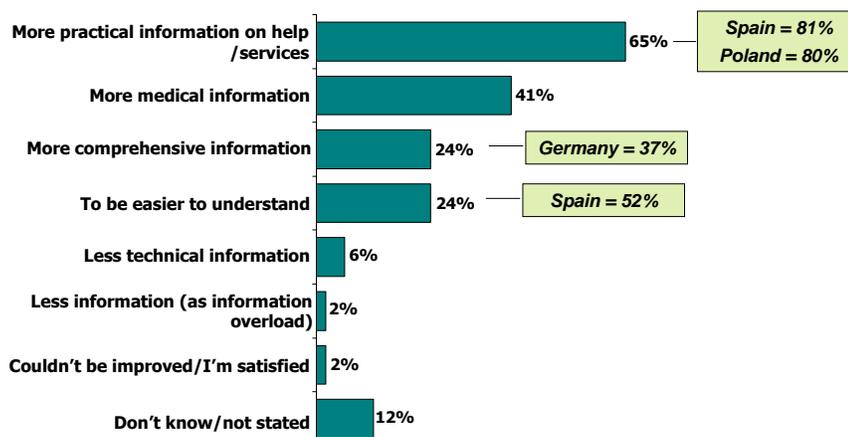
II.9 How should the diagnosis and other relevant information be given?

When asked how to improve the way that information is given, 65% of carers from the “Who Cares?” study stated that they would appreciate more practical information on help and services. This was particularly noticeable in Poland and Spain (81% and 80% of carers respectively).

Almost a quarter of carers stated that the information they receive should be more comprehensive and easier to understand.

Their responses are summarised in the following table.

Ways in which information received could be improved



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Information should therefore be provided in a sensitive and considerate way ensuring that the person with dementia can understand, and taking into account potential difficulties with memory, attention, concentration and understanding. Attention should also be paid to the person's level of education, reasoning capacity, cultural background, understanding of dementia, expectations and fears. Written information should always be provided as backup.

Concerning the actual diagnosis of dementia, Derksen et al. (2006) have developed a model for disclosure. They outline a number of issues. For example:

- Give the person time to react and express emotions. This may involve tolerating silence and perhaps reflecting back perceived emotions e.g. you seem to be quite shocked.
- Avoid giving too much information at once or too quickly as the person will not take it in until they have overcome the first shock.
- Ensure that it is the same person who discloses the diagnosis as was previously involved in the diagnostic process.
- Address the person with dementia directly even if accompanied by someone else.
- Be aware of the expectations of the person with dementia and the carer with regard to the diagnosis.
- Once the initial information has been provided and the person has had time for it to sink in, additional information can be provided about the test results, the prognosis and possible consequences on daily life. The person with dementia and carer should also have the opportunity to ask questions and be provided with written information.

General information on how to break bad news may also be useful (for an example, please refer to the following website <http://www.breakingbadnews.co.uk/guidelines.asp>).

II.10 How should Alzheimer associations be involved?

Details of an Alzheimer association, where the person with dementia and the carer can seek further information and support, should be provided at the time of diagnosis. This is mentioned in the “Recommendations for the diagnosis and management of Alzheimer’s disease and other disorders associated with dementia: EFNS guideline”⁷, where it is referred to as a “Good Practice Point” (European Federation of Neurological Societies, 2006 – in press).

Informing relevant medical professionals may necessitate the setting up of a system to ensure that they all have the relevant and up-to-date information that they need. This should include the contact details of the national association and the nearest branch, as well as details of the kinds of services that the association offers. Governments and professional medical bodies could play an important role in ensuring that medical professionals receive this information.

III Conclusions

Disclosure of the diagnosis of dementia is a complex issue involving the person with dementia, medical professionals and in many cases carers. As stated above, research indicates that many people with dementia would like to be informed of the diagnosis and would like carers to be informed too. Alzheimer Europe is of the opinion that people with dementia have a right to be informed of their diagnosis and that medical professionals should also be willing to involve carers (unless the person with dementia is opposed to this). The right not to be informed should also be respected.

Alzheimer Europe emphasises the need to provide people with dementia and carers with information about the disease, treatment and services at the time of diagnosis, and to ensure that every person receiving a diagnosis of dementia is given the contact details of the national and local Alzheimer associations.

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V Legislation, codes and conventions

Bulgaria: Law on health of 2005: http://www.mh.government.bg/doc/Law_on_Health_Jan_2006-en.doc

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<http://www.oup.co.uk/pdf/bt/cassese/cases/part3/ch16/1121.pdf#search='Convention%20on%20human%20rights%20and%20biomedicine'>

Cyprus: Law 1(I) 2005 to provide for the safeguarding and protection of the patients' rights and for related matters: [http://home.online.no/~wkeim/files/Cyprus-N.1\(I\)2005-English-translation.doc](http://home.online.no/~wkeim/files/Cyprus-N.1(I)2005-English-translation.doc)

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<http://www.retsinfo.dk/GETDOCI/ACCN/A19980048230-REGL>

Finland: Act on the Status and Rights of Patients (No.785 of 17 August 1992, amended in 1999)
<http://www.finlex.fi/fi/laki/kaannokset/1992/en19920785.pdf#search='Act%20on%20the%20Status%20and%20Rights%20of%20Patients'>

France: Décret no 95-1000 du 6 septembre 1995 portant code de déontologie médicale:
<http://admi.net/jo/19950908/SANP9502310D.html> (in French)

Greece: Rules of medical ethics and deontology: <http://www.alzheimer-europe.org/upload/SPTUNFUYGGOM/downloads/E854665B8E27.pdf> (p.35)

Greece: Article 47, Law No 2071/6-7-1992- Rights of Hospital Patients <http://www.alzheimer-europe.org/upload/SPTUNFUYGGOM/downloads/E854665B8E27.pdf> (p.24)

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http://www.szozolo.hu/53/rights_and_obligations_of_patients.htm

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Latvia: The law of medicine, 1997:
http://home.online.no/~wkeim/files/Latvia_The_law_of_Medicine.htm

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