

Alzheimer Europe

Recommendations on how to improve
the legal rights and protection of
adults with incapacity due to dementia

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Introduction

Background

The following recommendations are the end result of one year's work carried out by Alzheimer Europe¹, in collaboration with its member associations, legal experts and other concerned individuals. This was made possible through the financial support of the European Commission (under the programme "Support for transnational actions aimed at combating discrimination against elderly and/or disabled people", VS/1999/0226).

Building on the results of a previous EC funded project (the Alzheimer programme, SOC97 201298 05F03), which involved collecting, translating and comparing legislation relating to the rights of people with dementia from all member states of the European Union, Alzheimer Europe received additional funding to write recommendations on:

1. Guardianship measures
2. Restriction of liberty of movement and
3. Bioethical issues

Expert meetings were held and all member associations of Alzheimer Europe were given the opportunity to comment on the various drafts. In addition, the views of other associations and individuals with common interests were taken into account.

The underlying philosophy of the recommendations is the respect for human rights. This represents a break from much of the existing legislation in Europe, which apart from a few exceptions, is based on the protection of the person and/or his/her property. A key element in respecting the human rights of adults with incapacity due to dementia is the importance of an early diagnosis. Knowledge of the diagnosis is extremely important, if not essential, for numerous decisions which must be taken in the three areas covered by these recommendations. For this reason and also in view of recent medical advances in the treatment of Alzheimer's disease, we urge governments to take the necessary steps to ensure that an accurate diagnosis is obtained and given to the person concerned.

For whom are the recommendations intended?

Although the recommendations are specifically aimed at improving the legal rights and protection of people suffering from dementia, many of the articles may well be relevant and interesting to other groups of people (e.g. those with other forms of disability, those suffering from certain mental disorders, people with learning difficulties or severe illness etc.). At the same time, we acknowledge that there are special issues relating to gender, sexual orientation, disabilities additional to dementia and cultural diversity.

The term "*adults with incapacity*" has been used in preference to "*incapacitated adults*" in order to reflect the view that incapacity is not an all or nothing affair. The degree and

¹ Alzheimer Europe is an umbrella organisation for families and carers of people suffering from Alzheimer's disease and related disorders. It has 28 members in 23 different countries throughout Europe

nature of incapacity may differ from one person to the next, both within and between specific disorders or difficulties. Some people are unable to make an autonomous decision, others may only need assistance while others have the necessary capacity but cannot communicate their decision. Moreover, incapacity is not always static in that a person's capacity may fluctuate and/or progressively deteriorate.

Glossary

Before going any further, it is necessary to explain certain terms which will be used in the text.

Advance directive (living will)

An "*advance directive*" is a statement (preferably but not necessarily written) by a capable adult concerning his/her future treatment and care should s/he become incapable. Such statements often contain an advance refusal of specific treatment in certain circumstances. They may also contain details of the adult's desire to participate in therapeutic and/or non-therapeutic research, wishes concerning organ or tissue donation and preferences regarding residential care etc.

Best interests

"*Best interests*" should be understood to mean that which would be most likely to bring maximum benefit and/or wellbeing, and/or avoidance of suffering and/or loss to the person with incapacity. Although the interests of the family should not be ignored, the needs and interests of the person with incapacity should always come first.

Capacity and incapacity

The use of the words "*capacity*" and "*incapacity*", unless otherwise stated, should be understood in the context of and relating to autonomous decision-making. In the text, legal capacity/incapacity should be understood as referring to the legal recognition of an adult's ability to make autonomous decisions. Mental capacity/incapacity, on the other hand, should be understood as referring to a person's actual mental ability to make such decisions (in view of his/her state of mind and cognitive abilities) and should be task specific. Governments should encourage legal and medical institutions to work together on defining capacity and incapacity.² For an example of some of the ways that capacity can be affected in the case of Alzheimer's disease, please refer to the information sheet published by Alzheimer Europe or one of the existing descriptions of the various stages of the disease.

Consent

"*Consent*" should be understood in the sense of *informed* consent. This presupposes the ability to make, communicate, understand and/or retain the memory of a decision about proposed treatment, as well as the fact that the adult was not subject to undue pressure.

Court

The term "*court*" should be understood as referring to a formal and legally approved body/procedure responsible for handling the issue under discussion or making the appropriate decision in each respective country.

² For example, please refer to "Assessment of mental capacity, guidance for doctors and lawyers, a report of the British Medical Association and the Law Society", published by the British Medical Association in December 1995

Disability

The term “*disability*” as used in this text refers to a state of being unable, due to any physical or mental condition, of carrying out a task or function (physical or mental) which, were it not for the said condition, would be feasibly possible.

Guardian

The term “*guardian*” should be understood to mean a person who has taken on responsibility for decisions relating to the personal welfare and/or financial affairs of an adult with incapacity. S/he is primarily a representative of an adult and someone whose duty is to ensure that necessary decisions are taken and/or the proper care is provided. Not all guardians have a duty to care, though some have. In certain countries, the person fulfilling this task may be classed as a legal representative, tutor, curator, mentor, receiver, guardian or trustee etc. Each of these terms may represent different duties and responsibilities in different countries. This term should not be understood as referring to professional carers such as doctors and other medical staff, whose responsibilities are different. In these recommendations, “*guardian*” will be the term used when referring to all kinds of guardian - those appointed by a judicial authority and personally appointed guardians. Guardians must be appointed by the adult when capable using a lawfully approved procedure or by a court procedure.

Guardianship measures

The term “*guardianship measures*” refers to decisions about the organisation and provision of assistance by a third person on behalf of an adult with incapacity. This differs from the provision of services in the framework of a purely contractual agreement (e.g. meals on wheels and cleaning) in that a person is appointed who is personally responsible for making decisions and ensuring that the necessary steps are taken on behalf of an adult with incapacity, according to the nature and extent of the guardianship measure. Such decisions may be limited to either personal welfare or financial matters. Alternatively, they may cover both.

Judge

The term “*judge*” is used in the text to refer to the person who has been officially appointed by a formal legally approved procedure or body to handle a particular issue.

Mistreatment

“*Mistreatment*” is considered to include psychological, verbal and physical abuse, degrading or inhuman treatment, financial exploitation and the unjustifiable use of coercive measures etc.

Negligence

“*Negligence*” is understood to include failure to ensure the necessary means for survival and personal wellbeing (e.g. food, warmth, clothing, human contact etc.) and protection (e.g. supervision, guidance or avoidance of potentially dangerous situations etc.). It also includes failure to diligently carry out the task of care giving and to act as a proper representative. The term is intended to be a description of actions rather than a legal term denoting a crime or delict.

Personal advocate

A personal advocate is a person who is appointed to guide and advise an adult with incapacity in all matters relating to placement (both during and after the process to establish it), as well as whenever a measure intended to restrict his/her liberty of movement is applied. A personal advocate is not the same as a guardian. For full details, please refer to the section on “personal advocates” on page 23.

Placement

The term "*placement*" is used to refer to the placing of an adult in any institution or building, despite the fact that s/he objects or did not consent to this. This covers not only compulsory placement (sometimes referred to as forced internment/detention and involuntary placement) but also non-voluntary placement in a nursing home, care home or day care centre etc.

Research

"*Research*" should be understood as referring to the participation, monitoring or observation of an adult with incapacity or his/her behaviour, condition or personal details for the purpose of study or recording, e.g. scientific, statistical, observational, psychological, medical or clinical etc.

Restriction of liberty of movement

"*Restriction of liberty of movement*" is used in the text as a global term covering any limitation imposed on an adult's freedom to move about. This includes confinement to a building or room, as well as preventing the adult from physically moving within a particular space. As such it covers not only "placement" as described above, but any restriction of liberty of movement, including restraint. (Please refer to the recommendations on the restriction of liberty of movement for more details about the various forms of restraint.)

Should

The verb "*should*" has been used frequently throughout the text. This is not intended to imply a lesser degree of conviction or importance with regard to the points being made, but rather reflects the fact that the following are recommendations.

Treatment

"*Treatment*" is the term used to describe the administration or provision of care and medication, and the use of techniques with the aim of treating, safeguarding or promoting the physical or mental health of the adult with incapacity.

Guiding principles

- The current and prior will and wishes of the adult with incapacity (insofar as this can be ascertained) should be respected for all decisions taken on his/her behalf both at the hearing and throughout the period under guardianship and/or restriction of liberty of movement, as well as in relation to treatment, research and end of life decisions.
- The autonomy of the adult with incapacity should be maintained and enhanced as far as possible. Any interventions in the affairs of an adult should be the minimum necessary to protect the interests of the person, for the minimum time necessary.
- The interests of the adult with incapacity should come first. Therefore, his/her interests, personality, personal style and life history should be respected.
- Incapacity should be medically established and not simply based on the age of a person. However, the specific underlying psychological and social aspects of incapacity should be identified. Similarly, a medically established diagnosis of dementia should not itself suffice to establish incapacity.
- Decisions about any proxy decision-making during a person's incapacity should either have been made by the person whilst still mentally capable following a legally approved procedure, or be made by a court or in accordance with the equivalent judicial process/relevant law.
- There is a need for a global concept of welfare, covering psychological, medical, nursing and other personal care, but also financial welfare, citizenship, education in its broadest sense, leisure and spiritual needs.
- Capacity should be seen as relating to specific decisions or issues. Assessment of capacity should identify the range of capacities and incapacities of the person.
- Any restriction of liberty of movement or guardianship measure should be primarily and principally for the benefit of the adult, and not used as a means of control or punishment, or primarily for the benefit of another person.
- The use of protective or guardianship measures and/or restriction of liberty of movement should be balanced against respect of the adult's dignity and his/her right to self-determination.

Recommendations on guardianship (also known as legal representation)

Scope of the guardianship measure

1. The recommendations on guardianship are intended to cover the legal protection of adults with incapacity in relation to financial affairs and personal welfare. This includes personally appointed guardians and court appointed guardians. Certain issues, such as consent to medical treatment, organ donation and participation in research, will be addressed in the recommendations on bioethical issues.
2. As guardianship is a measure which entails allowing other people to act on one's behalf to a greater or lesser extent, the advantages of writing an advance directive and making arrangements for a personally appointed guardian³ (preferably a combination of the two) cannot be overemphasised. For this reason, we urge governments to set up the necessary structure to facilitate this.

CONCERNING THE ADULT WITH INCAPACITY DUE TO DEMENTIA

Restriction of a person's legal capacity

3. It should be presumed that an adult has capacity unless and until it has been proved that this is not the case.
4. A person's legal capacity should not be unnecessarily restricted. For example, if a person only needs assistance managing one aspect of his/her life, the guardianship measure should not result in a restriction of his/her legal capacity in other domains.
5. There should be no obligatory appointment of a guardian, even if the adult has incapacity, if such appointment is clearly not necessary.
6. The application of a guardianship measure should not involve the automatic loss of any legal rights, such as the right to marry, divorce, vote, make a will, drive or make a contract. However, should a person lack the necessary capacity for any or all of the above, his/her legal capacity may have to be restricted accordingly.
7. Although the guardianship measure may result in certain powers of representation being granted to the guardian to act on behalf of an adult with incapacity, this should not extend to the right to contract a marriage, divorce, make a will or vote on his/her behalf. On the other hand, s/he should be able to defend the interests of the adult with incapacity in certain domains.

³ Please refer to the relevant sections on advance directives and personally appointed guardians.

The right to self determination

8. The adult with incapacity should be involved as much as possible in the procedure to establish the guardianship measure and for the duration of it, including choosing the guardian and deciding on his/her duties.

CONCERNING THE GUARDIAN AND HIS/HER DUTIES

International recognition of guardians

9. In view of the ever-increasing mobility between countries, we recommend that the guardian of an adult with incapacity and the powers of this guardian should be recognised in another country⁴, except where actions taken by the guardian could contravene the laws of the other country.

Personally appointed guardians (e.g. powers of attorney/mandates)

10. The adult with incapacity should be able to apply to the relevant guardianship authority to request the appointment of a particular person as his/her guardian, whilst s/he is still sufficiently capable and hence able to do so.
11. An adult should also be able to appoint a person to make proxy decisions in relation to financial, welfare, health, research or other matters on his/her behalf in case of future incapacity. This could take the form of an “enduring power” which means that it *continues* to be valid even when the person who made it loses his/her mental capacity. Alternatively, it could take the form of a “springing power” which only becomes valid *once* the person has lost his/her mental capacity.
12. In both cases, this should involve a legal process and authorisation should be required. The power should be registered and a document produced, which can then be used as a means of proof and justification of the legitimacy of the guardian's actions. The moment at which the adult is considered to be incapable should be declared and the adult should have the opportunity to challenge this.

Court appointed guardians

13. The guardian should be suitable and have the required ability in view of the nature and scope of his/her task(s). The prospective guardian's suitability and fitness for the task should be determined by the judicial process of appointment in accordance with established criteria and should be subject to review. S/he must have consented to becoming the guardian of the adult with incapacity.

⁴ We recommend that Governments adopt the Hague Convention of 13 January 2000 on the International Protection of Adults

14. Certain people may be considered unsuitable to fulfil the role of guardian, as there could be a conflict of interests. Examples of this would include the director of an institution in which the adult with incapacity is residing and the treating doctor of the person with incapacity. The judge should decide whether a person is unsuitable on the basis of established criteria and should inform the person concerned of the reason.
15. In selecting a guardian, the judge should take into account and give preference to the prior or present wishes of the adult with incapacity. Such wishes could be expressed in an advance directive. For this reason, anyone who is aware of the existence of such a document should make it available to the judge.
16. It should be possible to appoint more than one guardian if this is in the interests of the adult with incapacity. For example, a person's interests might be best protected by the appointment of one guardian for financial affairs and another for his/her personal welfare. As personal welfare may be dependent on the amount of funds allocated, this could lead to conflict. In such cases, an arbitrator should be appointed or a legal procedure installed in which the conflict can be brought before a judge. It should be established whether multiple guardians can only act jointly or severally.
17. The setting up of professional guardianship organisations, which can provide trained, independent guardians, should be encouraged.

The duties and responsibilities of the guardian

18. The guardian must be informed by the court of the precise nature of his/her duties and responsibilities, as well as the extent of his/her power to act on behalf of the adult with incapacity. This should relate directly to specific incapacities.
19. The activities of the guardian should be subject to supervision and regular review, and should be monitored by a judge or another independent authority. This should apply to both court appointed and personally appointed guardians.
20. The guardian should have access to the necessary information and advice to carry out his/her duties effectively, as well as recourse to assistance if required.

Payment of the guardian

21. The guardian should not be allowed to profit from the guardianship measure, but should be allowed to receive adequate remuneration and reimbursement for any expenses incurred. In the case of trained, independent guardians from professional organisations, they should receive payment for their services.

Empowerment of the adult with incapacity

22. The guardian should be obliged to take into consideration the wishes of the person under his/her guard (insofar as this is possible) even if this person is considered to be

an adult with incapacity, particularly when trying to determine what would be in his/her best interests.

23. Furthermore, the guardian should be obliged to take into consideration the previously expressed wishes of the adult with incapacity e.g. with regard to accommodation, dress, food, choice of friends, having pets, the kind of care required and religious and spiritual needs/obligations etc. This should include those wishes expressed in the form of an advance directive. The guardian should also consult with significant others who may know about the wishes of the adult with incapacity.
24. The adult with incapacity should be kept informed of and consulted on decisions being made on his/her behalf, even when deemed to be mentally incapable. Information should be given in the way most appropriate to the person's remaining capacity.

Involvement of family and friends

25. In order to respect ties between the adult with incapacity and his/her spouse, partner, relatives and close friends, the guardian should be obliged to involve them when making decisions on behalf of the adult with incapacity, unless it is impracticable or against the best interests of the adult.

Avoidance of conflicts of interests

26. Provisions should be made to ensure that the guardianship measure and any actions by the guardian are in the interests of the adult with incapacity and not primarily in the interests of the guardian or any third party.
27. With regard to the protection of the financial interests of the adult with incapacity, guardians should ensure that the finances of the latter are used for his/her direct and current benefit (if and when appropriate) and not have as principal aim the augmentation or maintenance of his/her capital.
28. In any situation where there is a serious conflict of interests between the guardian and the adult with incapacity, the judge or another independent authority should either take a decision itself or appoint another guardian solely to handle the affair or issue in question.
29. There should be a procedure for people with incapacity to contest decisions made on their behalf by a guardian (including personally appointed guardians).
30. Anyone who has an interest in the wellbeing of the adult with incapacity and who suspects mistreatment should be able to anonymously report it to the relevant authorities, although a transparent complaints system should be encouraged.

31. In cases where the adult with incapacity has dependent children and his/her guardian is neither his/her spouse/partner nor a parent of the said children, their interests should not be defended by the person who is the guardian of the former. In such situations, a separate guardian should be appointed for the children in order to avoid a conflict of interests.

Liability of the adult with incapacity and the guardian respectively

32. With regard to civil responsibility, the adult with incapacity should continue to be liable for his/her actions and liable to pay compensation (in accordance with his/her economic situation). However, should s/he be in the care of or under the responsibility of another person, institution or body, the latter should be held responsible for damage caused by the adult with incapacity, only if it can be proved that s/he was grossly negligent in carrying out his/her duties. It should be recommended that s/he take out an insurance against such liability.
33. The guardian should be held responsible for any loss or damage caused to the adult with incapacity as a result of the guardian's deliberate actions, as well as for negligence and mistreatment of the adult. The adult with incapacity should be entitled to compensation. Consideration should be given to any actions taken in good faith which were intended to be in the person's best interests.
34. The adult with incapacity should not be held responsible for any injury or damage caused by the guardian whilst acting on behalf of the former.

CONCERNING THE GUARDIANSHIP MEASURE

The process of establishing the guardianship measure

35. Guardianship should not be arranged if a less far-reaching solution could be arranged.
36. The guardianship measure should be sufficiently flexible to allow an appropriate legal response, proportionate to the adult's actual needs and capacity. This might involve a series of different guardianship measures or one measure which can be adapted to the person for whom it is intended.
37. Guardianship should be established by means of a judicial procedure and there should be an appropriate administrative system to support this. Although the actual nature of the procedure may differ vastly from one country to another, the following issues should be incorporated into the procedure:
- there should be system to determine the range of responsibilities of the guardian;
 - the cost of the procedure should be kept to a minimum and should not be unnecessarily burdensome;
 - the duration of the procedure should be minimised;
 - the procedure should be straightforward;

- medical experts and psychologists should be involved in the procedure of determining the person's incapacity. Reports from social workers should also be required. (As stated in the principles, incapacity should not be simply based on age or a diagnosis of dementia);
- the exact duties, responsibilities and powers of the guardian should be specified, including those for which additional authorisation is required;
- the appropriate measures should be taken in order to ensure and maintain discretion and respect for the privacy and human dignity of the adult with incapacity at all times;
- there should be readily available and easily accessible information on the guardianship procedure, as well as the possibility of obtaining help and advice (not only on the procedure but also on the consequences of guardianship);
- it should be possible to arrange an interim guardianship measure if required e.g. in case of emergency. This could be a temporary guardian with limited powers;
- the adult presumed to have incapacity should be able to appeal against the loss of legal capacity and/or the guardianship measure.
- It should be obligatory that the adult with incapacity is present during the procedure to establish guardianship and that s/he is also heard by the judge or equivalent authority. If it is not possible or impracticable for the adult with incapacity to be present in court, arrangements should be made for him/her to be seen and heard by the judge elsewhere.
- A guardian should be appointed to represent the adult with incapacity and protect his/her interests at the process, if the judge or equivalent authority deems that this is necessary even if the adult with incapacity has not asked for one.
- If the adult with incapacity so desires, s/he should be allowed to appoint a person to speak on his/her behalf in court. This should not alter the necessity for the judge or equivalent authority to see and hear him/her as well in person.

The process of review and supervision

38. The guardianship measure should initially be arranged for a set period of time (which could vary according to necessity). After this time, there should be a reassessment of the situation, the guardian's suitability and the needs of the adult with incapacity. Should it be necessary for the guardianship measure to be continued, it should be possible for the guardian to continue in his/her function for a renewed period of time. If the guardian is no longer suitable (e.g. due to incapacity or severe illness etc.) or is unwilling to continue, another suitable guardian should be found to replace him/her. This process should be continued for as long as it is necessary.
39. In addition, there should be a periodic review of the guardianship measure. Such review should consist of at least an annual report on the accounts, welfare and medical condition of the adult with incapacity, which should be submitted to an appropriate supervisory authority.

40. The guardian should have to keep records (particularly financial guardians). Guardians should be able to be sacked or replaced at any time if they do not carry out their duties in accordance with good practice – not just at times of review.
41. Should the guardian be the spouse, partner or other person living communally with the adult with incapacity, s/he should only be obliged to provide justification for expenditure once a specified ceiling or percentage has been reached.
42. The guardian should grant representatives from the appropriate supervisory authority access to the adult with incapacity in order to enable them to assess and ensure his/her wellbeing.

Recommendations on limits for the restriction of liberty of movement

GENERAL PROVISIONS

Scope and applicability of the measure on limits on the restriction of liberty of movement

1. The recommendations on the restriction of liberty of movement are intended to cover the legal protection of adults with incapacity due to dementia who may be considered to require restriction of their freedom of movement against their will or without their consent. This includes:
 - restriction of liberty of movement within a private home;
 - placement in a care establishment (e.g. a care home, nursing home or day care centre);
 - placement in a psychiatric institution or psychiatric hospital/ward, and
 - the use of any mechanical, chemical, psychological, technological or physical means/measures to restrain or limit the adult's liberty of movement, wherever it may occur and irrespective of whether the adult has been placed against his/her will or without his/her consent.

Appropriateness of restrictive measures

2. Restriction of liberty of movement should not be used:
 - until all other less restrictive measures have failed;
 - until all possible steps have been taken to obtain the adult's voluntary co-operation;
 - to a greater extent than is necessary;
 - for longer than necessary;
 - to counteract staff shortages, lack of professional skill or defects in the environment;
 - as a means of control or punishment;
 - if use could cause serious damage to the adult with incapacity or endanger his/her recovery.
3. Restriction of liberty of movement should be carried out with the utmost consideration for the adult and as gently as possible, so as to avoid any unnecessary discomfort, inconvenience or affront to his/her wellbeing and dignity. The predominance of his/her interests should be ensured, with an emphasis on the individual and not the type of institution into which s/he may be placed.

4. Restriction of liberty of movement should also be carried out with consideration for the family of the adult with incapacity, so as to avoid any unnecessary inconvenience or affront to the dignity and sensibility of the family.

PROCEDURE FOR RESTRICTING THE LIBERTY OF MOVEMENT

Placement

Conditions for placement

5. Involuntary placement and treatment should be exceptional. Moreover, it should be understood that a distinction must be made between the legal grounds for involuntary placement and the legal grounds for involuntary treatment and that even if the adult was admitted involuntarily, the presumption of competence to decide upon his/her treatment should prevail.
6. In order for an adult with incapacity due to dementia to be either placed against his/her will or without his/her consent or be subjected to measures to restrict his/her liberty of movement, the following conditions should apply:
 - Placement is necessary for treatment or for therapeutic reasons (that correspond to his/her clinical condition and his/her socio-economic situation) and the adult is either unable or does not want to consent to it; AND
 - i) Failure to apply the measure would result in a serious deterioration of his/her health and/or condition OR

S/he is a danger to him/herself⁵; AND/OR s/he is a danger to others⁶ AND
 - ii) There is no less restrictive alternative available.
 - Placement is necessary for the provision of care, the adult is unable or does not want to consent to it and there is no advance directive or instructions for a personally appointed guardian, AND subsections i) and ii) above apply.
7. In the case of placement solely for care, a guardian should be appointed with responsibility for deciding on the place where care should be provided.
8. The care and/or treatment (which should be understood to include the use of restraint) should correspond to the needs of the adult and be administered in the place most appropriate to these needs. If, however, the most appropriate place for a particular adult with incapacity is a psychiatric institution and such placement is not possible,

⁵ e.g. s/he is a proven fire hazard, has wandered onto busy roads, his/her health is seriously deteriorating as a result of malnutrition or lack of hygiene or has had a serious of falls with severe consequences.

⁶ e.g. s/he has attacked, injured or seriously endangered the life or health of other people.

s/he may be placed in non-psychiatric establishment, although this must be able to meet the person's care and/or treatment needs.

9. When placing an adult with incapacity in an establishment where there are also capable adults, attention should be paid to the ability of staff and the establishment to cater for his/her specific needs, as well as other consequences of such a placement for the adult with incapacity.
10. Failure to respect the correct procedure and conditions with regard to the restriction of liberty of movement should result in specific sanctions and compensation for the adult with incapacity.

Procedure for arranging placement

11. Any family member or other person close to the adult who is concerned about his/her wellbeing should be able to request that s/he be placed in an appropriate establishment. However, there should be a formal and legal/administrative process to determine whether and, if appropriate, where the adult should be placed. The following issues should be considered:

The procedure itself

- the cost of the procedure should be kept to a minimum and should not be unnecessarily burdensome;
- the duration of the procedure should be minimised;
- the procedure should be straightforward;
- attention should be given to discretion, privacy, respect for human dignity and avoiding making the adult feel like a criminal;
- there should be readily available and easily accessible information on the placement procedure, as well as the possibility of obtaining help and advice (not only on the procedure but also on the consequences of placement);
- it should be possible to arrange an interim placement measure if required e.g. in case of emergency.

Who should be involved?

- the adult, his/her family, the guardian and/or any person close to the adult should be consulted, provided that the adult has given his/her consent to this consultation (as the interests of the aforementioned are not always the same as those of the adult with incapacity) - unless there are wider issues of public safety which mean that family members and close persons can be consulted without the adult's authorisation;
- independent medical experts (other than the director or experts of the same institution) should be involved in the procedure of determining the person's incapacity (as stated in the principles, incapacity should not be simply based on age or a diagnosis of dementia);

- a personal advocate⁷ should be appointed for the adult;
- a judge or other independent authority should always either be involved in the process or authorise the decision afterwards, or if emergency procedures were applied, authorise or reverse the decision afterwards;
- the adult should have the opportunity to be heard, so if s/he does not appear or have a legal representative someone should be appointed to represent his/her interests at the hearing.

Concerning the decision

- the placement of an adult with incapacity should not be sufficient in itself to limit his/her legal capacity in any way;
- the duration of the initial placement should be specified;
- the kind of establishment which would be most appropriate should be decided upon and this choice alone should not have repercussions on the adult's legal capacity;
- attempts should be made to place the adult as near to his/her home, family and friends as possible;
- it should not be possible to transfer the adult once placed unless this would be in his/her best interests;
- the adult, his/her family and the guardian should all be informed of the decision;
- the measure should be applied as soon as possible after the decision has been made.

Emergency placement

12. In case of emergency anyone should be able to inform a doctor or the police of their concern about the welfare of an adult with incapacity. In all cases, a doctor must see the adult before the latter can be temporarily kept against his/her will or without consent in an appropriate place. The doctor should then report the emergency placement as soon as possible (within 72 hours) to the court or relevant authority which should then have the duty to approve the measure or rescind it and if necessary to order court proceedings to establish placement or the appointment of a guardian.

Appeal, review and control

13. The adult should be allowed to appeal against the placement. His/her personal advocate may help him/her with the appeal. Any other person with an interest in his/her personal welfare should be able to also appeal against the placement (including its appropriateness).

14. There should be a regular review at intervals of 6 months of the necessity and appropriateness of the placement. A time limit should be set for this review. If the

⁷ Please refer to page 23 for details about the role and duties of a personal advocate.

placement is no longer necessary or appropriate, it should be brought to an end or amended accordingly.

15. It should be possible for the relevant authorities to inspect places where adults with incapacity have been placed against their will or without their consent, and on any such visit to have free access to the person and all members of staff, medical advisors etc. for interview, and all records held about the person. It should not be necessary to arrange this beforehand with those in charge of the institution/home.

Restraint

Conditions for the use of restraint

16. The same conditions as those for placement should apply to the use of restraint, including that used in the adult's own home or his/her place of residence against his/her will or without his/her consent. In addition to the conditions, the following procedure and guidelines should accompany the use of restraint. In a few cases, it will be clear from the text that an article is only applicable in a formal care setting (e.g. hospitals, care homes and day care centres etc.), although on the whole the text should be considered as destined for both formal and informal carers (i.e. professional and non-professional).

General procedure surrounding the use of restraint in the formal care setting

17. The use of various forms of restraint cannot be justified if placement in a different kind of establishment would be possible and would render such measures unnecessary.
18. The use of restraint should be prescribed by a doctor who has personally seen the adult and should be registered in a readily available document in which the reason, means and duration are stated. This should be signed by the doctor or consultant who prescribed the measure.
19. The guardian should be informed (if personal welfare is one of his/her duties).
20. In situations where the adult with incapacity risks causing serious harm to him/herself or others and it would not be in the adult's best interests to delay action until a doctor arrives, other nursing staff should be allowed to use restraint other than chemical restraint. In such cases, this should be immediately reported to the doctor or consultant, who should mention this in his/her report and decide upon its continued use.
21. The patient or his/her representatives should be able to request at regular intervals a review of the lawfulness and/or need for the continued use of restraint.

22. Responsibility for the wellbeing of the adult with incapacity during the application of restraint should lie not only with the doctor who prescribed it but with all members of staff involved in his/her care and/or with his/her guardian, provided that personal welfare is one of his/her duties.
23. The personal advocate should be informed of any use of restraint and should be allowed to see the adult. The adult should be allowed to request to see his/her personal advocate whenever s/he has been or is being subjected to the use of restraint.
24. The continued use of restraint should be reviewed on a frequent and regular basis. The person responsible for its initial use should be responsible for any prolongation of the measure, which should also be reviewed by an independent person/team. A time limit should be established for various forms of restraint, after which the continued use of it should be evaluated.
25. In the case of prolonged use of restraint (or if the extent and/or duration necessitate it), this should be referred to a court or independent authority to ask for authority to continue.

Guidelines on the use of various measures designed to restrict liberty of movement

26. Guidelines on the use of restraint have been drawn up and can be found in Appendix 1. This represents a first attempt at addressing this issue and it is hoped that they will be discussed by multi-disciplinary groups on a national and European level in the course of the next year and the relevant changes made. The guidelines were heavily influenced by a report produced by the Mental Welfare Commission for Scotland⁸, although it should be noted that guidelines have also been produced in Sweden.

THE RIGHTS AND PROTECTION OF ADULTS WHOSE LIBERTY OF MOVEMENT HAS BEEN RESTRICTED

The rights of adults whose liberty of movement has been restricted

27. An adult, whose liberty of movement has been restricted, should have the following rights:
 - the right to be treated with respect,
 - the right to privacy and respect of private life,
 - the right to complain and appeal against measures,
 - the right to speak to his/her personal advocate
 - the right to receive visits,
 - the right to communicate with the outside world (including sending unopened letters),

⁸ Mental Welfare Commission for Scotland (1998) "Restraint of residents with mental impairment in care homes and hospitals: principles and guidance on good practice in caring for residents with dementia and related disorders and residents with learning disabilities".

- the right to adequate stimulating and/or meaningful activities, as well as exercise,
- the right to go out in the fresh air on request for times equivalent to their previous normal habits,
- the right to outdoor access within a safe area,
- the right to practice religious, spiritual and ideological beliefs,
- the right to respect for his/her sexuality,
- the right to wear his/her own clothes,
- the right to keep personal items in his/her room,
- the right to be informed of decisions concerning him/herself,

Personal advocates

28. A personal advocate should be appointed to guide and advise the adult in all matters relating to placement both during and after the process to establish it, and also whenever a measure intended to restrict his/her liberty of movement is applied.
29. The advocate should be independent from the institution or place where the adult is residing, as well as from the family. Although such an advocate could be appointed arbitrarily (e.g. the next person on a list of available advocates), the adult should be able to refuse a particular advocate and ask for an alternative at any time. It should be possible for a family member to be the personal advocate in certain circumstances.
30. The advocate should visit the adult on a regular basis and have unhindered personal, written and telephone contact with him/her - in private if necessary. If required, s/he should assist the adult in making a complaint.
31. S/he should be provided with any information necessary to allow him/her to carry out his/her duties effectively, but no more than is necessary on a need to know basis. Personal information which the person would not wish his/her advocate to know should be withheld.
32. In case of suspected mistreatment or negligence, the advocate should inform the person responsible for the care of the adult and make a report. Should the situation not be rectified within a reasonable period of time and/or be of a serious nature, s/he should contact the relevant authorities in order to ensure that the necessary steps are taken to protect the adult. The family and/or guardian of the adult should also be allowed to contact the advocate in cases of suspected mistreatment or negligence, although they should be able to complain to the relevant authority directly if they so desire.
33. Personal advocates should be knowledgeable about dementia, familiar with the relevant legislation governing placement and restriction of liberty and have an awareness of the issues surrounding mistreatment and negligence. Literature containing relevant information should be made available if requested.

34. A Code of Practice for Advocates should be drawn up and a system devised to monitor standards.
35. Should the adult with incapacity not wish the personal advocate to act for him/her, this should be reported to the relevant supervisory authority so that more external scrutiny of the person's placement/restraint can take place.

Recommendations on bioethical issues

Information about one's state of health/diagnosis

Access to information

1. The adult with incapacity has the right to be informed about his/her state of health.
2. Information (including literature where appropriate) should, where appropriate, cover the following: the diagnosis, the person's general state of health, treatment possibilities, potential risks and consequences of having or not having a particular treatment, side-effects, prognosis, alternative treatments, the availability of services to which the person is entitled, the name of the doctor who has overall responsibility for the adult's care/treatment and the name of any key worker with special responsibilities in his/her care.
3. Such information should not be withheld solely on the grounds that the adult is suffering from dementia and/or has communication difficulties. Attempts should be made to provide information in such a way as to maximise his/her ability to understand, making use of technology and other available techniques to enhance communication. Attention should be paid to any possible difficulty understanding, retaining information and communicating, as well as his/her level of education, reasoning capacity and cultural background. Care should be taken to avoid causing unnecessary anxiety and suffering.
4. Written as well as verbal information should always be provided as a back-up. The adult should be granted access to his/her medical file(s). S/he should also have the opportunity to discuss the contents of the medical file(s) with a person of his/her choice (e.g. a doctor) and/or to appoint someone to receive information on his/her behalf.

Withholding and the refusal of information

5. Information should not be given against the will of the adult with incapacity.

Provision of information to third parties

6. The confidentiality of information should extend beyond the lifetime of the adult with incapacity. If any information is used for research or statistical purposes, the identity of the adult with incapacity should remain anonymous and the information should not be traceable back to him/her (in accordance with the provisions of national laws on respect for the confidentiality of personal information). Consideration should be given to access to information where abuse is suspected.

7. The next of kin and partner of the adult with incapacity should be informed of the diagnosis of dementia if they so request, unless the adult requests or previously requested that they should not be informed.
8. A clear refusal by the adult with incapacity to grant access to information to any third party should be respected regardless of the extent of his/her incapacity, unless this would be clearly against his/her best interests e.g. carers should have provided to them information on a need to know basis to enable them to care effectively for the adult with incapacity.
9. People who receive information about an adult with incapacity in connection with their work (either voluntary or paid) should be obliged to treat such information with confidentiality.

Representation of the adult with incapacity by third parties

10. If, due to the nature and extent of his/her incapacity, the adult cannot make a decision, s/he does not have a guardian with responsibility for such decisions and there is no advance directive or provisions for a personally appointed guardian, a guardian should be appointed with responsibility for treatment and care decisions.
11. Access to information (including the medical file) that would normally have been granted to the adult with incapacity should be given to the guardian if necessary and reasonable to do so. Such disclosure should not be against the best interests of the adult with incapacity.
12. Permanent judicial support should be guaranteed for decisions taken on behalf of adults with incapacity.

Involvement in the decision making process

13. The adult with incapacity should, whenever possible, be involved when decisions are being made on his/her behalf. Guardians should provide him/her with the necessary information, take into account his/her opinion and keep him/her informed of any decisions made (as well as the consequences of such decisions). His/her past, present and presumed wishes should be respected, provided that this is possible and not against his/her best interests (unless expressed in an advance directive, in which case, it is good practice to respect the person's wishes, even if they are not in the person's best interest, unless this would lead informal or formal carers to act unlawfully). In addition to taking account of the adult's wishes, immediate carers and relevant family members should be consulted.

Consent to treatment

14. Informed consent must be obtained before treatment can be given, except in the circumstances described below. Such consent may be explicit or implied. It should

not be presumed that the adult cannot give informed consent to treatment purely on the grounds that s/he has incapacity.

15. A doctor should be allowed to decide on non-radical or routine treatment on behalf of the adult with incapacity, having ascertained his/her incapacity, if a guardian is not readily available. This should be noted in the adult's medical file. The doctor should have some kind of approved special training in the assessment of capacity. (All countries have separate laws in relation to the treatment of mental disorders.)
16. The removal of body tissue or substances for routine medical procedures linked to the treatment of the adult with incapacity should not necessitate additional consent procedures.
17. Should the adult with incapacity be unable to consent to treatment of a more serious nature, a guardian should be able to consent (or refuse) on his/her behalf. In order to do so, s/he should be provided with the necessary information to make a decision and his/her identity should be recorded for future reference. If none is available or willing to make this decision, the doctor responsible for the adult's treatment should decide according to the principle of best interests and inform the guardian as soon as possible. S/he should obtain a second medical opinion in cases of any complexity.
18. When consenting to treatment on behalf of the adult with incapacity, a guardian should take into account his/her previously expressed wishes, as well as his/her present and presumed wishes in order to make a decision.
19. Guardians should not be permitted to refuse treatment that is necessary to ward off a threat to the life or health of the adult with incapacity, unless this is in line with the adult's previously expressed wishes.
20. If an adult with incapacity refuses or resists treatment, doctors should have to apply to court or an independent authority in order to proceed with the treatment. This should also be applicable in cases where someone has consented on behalf of the adult with incapacity, and where the adult with incapacity first consented (e.g. in an advance directive) and then withdrew consent or refused treatment.
21. In case of refusal, doctors should continue caring for the adult with incapacity in another medically acceptable manner, which is in accordance with the wishes of the person who refused consent.
22. If the doctor responsible for the care of the adult with incapacity disagrees with a decision made by a guardian, s/he should not be bound to abide by it, as his/her personal convictions should be respected. In such cases, s/he should obtain a second medical opinion and if necessary ask another doctor to carry out the treatment.

Consent to research

23. It proved impossible to reach a consensus on the question of research involving adults with incapacity. However, two sets of questions arose which proved useful:

- i. Should research into dementia be carried out? Should research into treatment (including scanning techniques) be carried out? Should other kinds of research (e.g. investigations, lifestyle, etc.) be carried out?
- ii. If so, where should the limit be set as to how much an adult with incapacity should be harmed or benefit from such research?

It was agreed that such research should be possible with adults with incapacity but that clearly participants should not be harmed. This led to the formulation of conditions which should be fulfilled, should the adult with incapacity be unable to consent him/herself to participation in research (and where s/he has not covered this issue in an advance directive).

24. If the adult with incapacity is unable to consent to research, it should be possible for a guardian to consent on his/her behalf provided that:

- the guardian has been specifically authorised to do so by a court;
- the risk of causing discomfort or distress is limited;
- the interests and wellbeing of the adult with incapacity are always placed ahead of the interests of science and society. It should only be possible to expose an adult with incapacity to such procedures whose health or scientific benefit is expected to be clearly greater than the possible risks and disadvantages to him/her, and if risk is minimal;
- the necessary safeguards have been taken to protect the adult's privacy and to respect his/her dignity;
- it has been approved by an independent ethics committee. This committee should be responsible for verifying that the necessary precautions have been taken to safeguard the well-being, safety and dignity of the adult with incapacity.
- it should be possible to stop participation if the adult with incapacity shows any distress or negative reaction.
- the same results could not be obtained with other subjects;
- the benefits of the research are expected to be beneficial to other people with a similar medical condition.

25. In view of the differing views concerning the involvement of adults with incapacity in research, the following recommendations were made:

- Campaigns should be organised to encourage people to write advance directives which cover participation in research;
- The whole issue of research involving adults with incapacity should be investigated and discussed;

- Alternative or complementary methods of experimentation should be considered;
 - The possibility of developing non-placebo drug trials for adults with incapacity due to dementia should be considered.
26. The adult with incapacity should be involved in the decision making process. S/he should be informed about what is involved, as well as the aims and consequences of the research. It should be made clear to him/her (at regular intervals if necessary) that s/he is not obliged to participate and can withdraw at any time from the research or from any procedure associated with it.
27. In cases where the decision was not taken by the adult with incapacity, a guardian should also be able to request that s/he withdraw at any time, irrespective of whether s/he was responsible for the original decision, but only based on the best interests of the adult with incapacity, never for a simple change of mind and always with a clear idea of the consequences of withdrawal.

Consent to tissue and organ donation

28. It should not be permitted to remove non-regenerative body tissue/substance or organs - for a graft or transplant to another human being - from a living adult with incapacity. In the case of regenerative body tissue/substance or organs, removal for a graft or transplant to another human being should be possible if approved by a court authority.
29. The guardian should be able to consent to the removal of tissue or organs on behalf of the adult with incapacity, provided that the removal is *solely* in the best interests of the adult with incapacity, that s/he does not object and that s/he did not refuse such removal in principle whilst still capable. If s/he objects, the operation should only proceed if failure to do so would seriously endanger his/her health or life.
30. The removal of body tissue or substance for the purposes of research from a deceased adult with incapacity should be permitted provided that s/he did not object whilst still capable. If there is no research protocol, there should be co-operation between different countries to enable and facilitate the exchange and sharing of donations.

Advance directives

31. The adult with incapacity should be informed about the possibility of writing an advance directive before his/her incapacity reaches the stage that s/he is no longer able to do so. Guidance from a doctor is advisable in order to ensure that the advance directive is clear, in line with modern practice and that the adult with incapacity is aware of the consequences of his/her choices. Guidance from a doctor should be obligatory in cases where there is doubt about the person's capacity to make the directive. Please see Appendix 2 for one possible example of such a document.

32. A copy of the advance directive should be given to the doctor of the adult with incapacity and its existence should be clearly recorded in his/her medical records. It should be expected that doctors treating the adult with incapacity will seek an advance directive. The original advance directive should eventually be given to the guardian. In addition, in order to guarantee that advance directives are public documents, various ways of publicising them could be envisaged:
- A copy could be kept by a notary;
 - A national register could be created of all advance directives (and co-operation between countries encouraged);
 - Computerised medical files could systematically include details about advance directives (in accordance with the provisions of national data protection laws).
33. As the contents of an advance directive may in time become inappropriate or illegal, people should be encouraged to periodically review them and/or confirm their agreement with the content whilst still able to do so. It should be possible to include a clause stating that wishes should be respected unless medical advances have rendered them invalid.
34. Any part of an advance directive asking someone to act in an illegal fashion would not be valid.
35. Medical staff who are not familiar with the medical history and details of the adult with incapacity should as a routine measure find out whether s/he wrote an advance directive. If any person deliberately withholds an advance directive written by an adult with incapacity, s/he should be held legally responsible.
36. Guardians should be obliged to respect preferences expressed by the adult with incapacity in an advance directive when making decisions on his/her behalf.
37. Preferences stated in an advance directive concerning life saving, maintaining or prolonging treatment should be legally binding.
38. It should be possible to challenge the non-respect of an advance directive (subject to the limitations in different countries).
39. If a doctor, who is unaware of the existence of an advance directive, acts in the best interests of an adult with incapacity, s/he should not be liable for failure to respect the latter's wishes stated therein, provided that s/he made the necessary enquiries in relation to best practices within the member country.
40. If a doctor is unwilling to respect any wishes expressed in an advance directive, this refusal should be respected, provided that s/he has justifiable reasons (e.g. personal convictions, religious beliefs etc.). However, s/he should attempt to find another doctor to carry out the wishes of the adult with incapacity provided that such a wish is

not contrary to the national law of the member country. If this is not possible, the court authorities should decide upon the matter.

41. If the doctor simply ignores or fails to respect wishes expressed in an advance directive for no justifiable reason, there should be a possibility of sanctions being applied.

End of life decisions and rights⁹

Treatment and care decisions

42. When the adult with incapacity reaches an advanced stage of the disease or is nearing the end of his/her life due to another disorder or illness, s/he should be entitled to palliative care in order to alleviate his/her physical and psychological suffering. Such care should be provided either in an institution/hospital or at the adult's home.
43. If painkillers are needed, the necessary dose should be administered even if this might entail a risk of shortening the life of the adult with incapacity.
44. The wishes of the adult with incapacity with regard to the relentless pursuit of treatment when there is no hope of recovery, cure or improvement should be respected.
45. Specially trained medical staff should assist the dying person until the end, safeguard his/her dignity and provide the necessary support to preserve the quality of his/her life.

Rights of the dying person

46. An adult with incapacity who is approaching the end of his/her life should be ensured a dignified death.
47. S/he should be treated with respect.
48. His/her need for privacy and/or company should be respected.
49. As the adult with incapacity approaches death, s/he should have the right to be permanently accompanied by at least one person of his/her choice in conditions which permit his/her dignity to be maintained.
50. The religious or spiritual beliefs of the adult with incapacity should be respected. S/he should be allowed access to a representative from a church or group sharing his/her beliefs if requested.

⁹ We recommend that governments and the relevant authorities respect the provisions of "Recommendation 1418 on the Protection of the Human Rights and Dignity of the Terminally Ill and the Dying" of the Council of Europe (1999).

Rights of those accompanying the dying person

51. The family and friends of the adult with incapacity should also be treated with respect. They should be provided with adequate understanding and assistance to relieve their suffering.
52. Governments should ensure that family members and/or the close person responsible for the care of the dying person are granted sufficient time off work to care for and accompany him/her.

Appendix 1

Guidelines on the use of various measures designed to restrict liberty of movement

- Care should allow for some degree of risk taking. Therefore, a balance should be achieved between the adult's personal autonomy and the use of restraint as a means of care and/or protection.
- The restriction of an adult's liberty of movement should be avoided as far as possible. If restraint is deemed necessary, the adult's behaviour should be assessed in order to try to determine why the measure proved necessary. Attention should be paid to possible contributing factors such as pain, discomfort, side effects of drugs, psychological stress, poor relationships and incompatibility between the adult and his/her carers etc.
- If no remedial cause can be found, the risk of not restraining the adult should be considered. S/he should only be restrained if the risk is considered to be unacceptable, i.e. the consequences of not applying restraint would be detrimental to the adult's wellbeing (medical, psychological or other) and that the benefits of doing so outweigh any possible negative outcome.
- Whenever possible a multidisciplinary team should be involved in decisions about the use of restraint.
- In applying restraint, attempts should be made to explain to the adult what is happening, why, how long the measure is likely to last and who will be available during the period of restraint.
- The risk of injury resulting from the use of restraint should always be borne in mind. Consequently, there should always be at least one member of staff/carer present (in visual and verbal contact) for as long as the adult is subjected to the measure of restraint. This may necessitate measures to ensure that there are sufficient members of staff available, particularly at night.
- Any person who is involved in the application of measures of restraint should have received training in non-restrictive methods of care as well as in the use of restraint. Unless unavoidable or impractical, a male member of staff should not be employed to restrain a female.

Mechanical restraint

Definition: The use of special furniture, clothing or devices to prevent a person from moving his/her body or from leaving a defined place/space, i.e. special chairs with fixed trays, commodes, straps, belts, gloves, cot sides, secure sleeping bag and straitjackets.

Mechanical restraint should never be used solely to reduce restlessness. In such cases, the adult should have a physical examination and his/her medication should be reviewed. If possible, mechanical restraint should not be applied until less restrictive and then if necessary manual means have been tried. In all cases, the following alternatives should be considered before such restraint is used:

- Increase supervised exercise time (this may also improve mobility and reduce the risk of falling);
- Reorganise and if possible increase the number of staff involved in observation and supervision tasks;
- Change the pattern of rest periods in bed;
- Provide seated activities, which occupy the attention of the individual or group;
- Make imaginative use of diversional or occupational therapy;
- Use special environments if available (e.g. Snoezelen rooms).

Attention should be paid to environmental factors such as temperature, noise level, lighting, overcrowding, ease of observation and the restrictive or oppressive use of space and doors.

If chairs are used which restrict the adult's movement, they should be comfortable, individually fitted to the adult's requirements and provide a certain degree of freedom of movement. They should not be used indiscriminately or as a means of seclusion.

Under no circumstances should the adult (or his/her limbs) be tied to a chair or put in a straitjacket.

If cot sides are used as a means of restraint, attention should be paid to the possibility that the adult may try to get out of bed and injure him/herself in the process. An alternative approach would be to put a mattress on the floor, provided that this could be done in a way that would not be demeaning to the adult.

Physical restraint

Definition: The actual or threatened laying of hands on a person to prevent him/her from embarking on a movement or following it through.

Staff and carers should be trained in how to physically handle adults in this way, as incorrect use of this means of restraint could cause injury. It could also be

interpreted as an attack and provoke a reaction of fear, perhaps further exacerbating the situation.

Locking doors

Adults should not be confined to one room by means of a locked door or any other means of restraint, irrespective of whether they have been placed. It should only be possible to restrict a person to several rooms or to particular spacious areas.

The locking of doors other than in the context of placement

Doors should not be locked unnecessarily. Attention should be paid to interior design in order to avoid drawing attention to the exit, but also to ensure that it is visible to staff and carers for the purpose of supervision. Residents for whom there is no justification to restrict their freedom of movement should not be prevented from leaving the building or room due to restraint measures intended for others.

Tagging

Definition: The attachment of an electronic device to a person or to his/her clothing, so that when s/he crosses a particular boundary an alarm goes off and the staff or carer is alerted. Similar devices can also be used to monitor the whereabouts of the person and trace him/her if deemed necessary.

Tagging should only be used if the adult is at serious risk of wandering and all other methods have been tried and have failed. If used, the tag should be unobtrusive (so as to avoid possible feelings of humiliation and also stigmatisation) and not be uncomfortable to wear. The use of tags should enhance freedom of movement rather than restrict it.

Video surveillance

Definition: The use of video equipment to observe and monitor defined areas, e.g. day rooms, corridors, door areas and in some cases personal space.

Video surveillance in public areas should only be used with the consent of patients, residents or visitors, particularly as it is an indiscriminate means of restraint and could be considered as an invasion of privacy. If this is not possible, consent should be obtained from the guardian.

Ordinarily, there should be no justification whatsoever for the use of video surveillance in private living areas such as bedrooms, bathrooms and toilets. In exceptional circumstances (i.e. where its use is considered to be the least intrusive measure available), video surveillance should be permitted in private living areas

solely with the consent of the adult with incapacity (if s/he is able to give it) or failing this of the guardian and/or close relatives. In such cases, the reasons for such surveillance should be considered and stated within a care plan, it should be for a time-limited period and the decision should be reviewed on a regular basis (preferably daily).

Passive alarms

Definition: The use of pressure pads (e.g. under mattresses or rugs), infra-red alarms and sound monitors to signal a person's presence or movement.

Passive alarms are generally considered to be less intrusive and obvious than video surveillance. However, the alarm should not be too loud or disturbing and there should of course be sufficient staff or carers available to attend to it. If possible, the adult should be informed of the measure and receive a simple explanation of how it works. The use of an alarm should be considered as a possible alternative to locking doors.

Medication as restraint

Definition: The use of sedative or tranquillising drugs for purely symptomatic treatment of restlessness or disturbed behaviour (i.e. not for the treatment of the condition underlying the disturbance but rather in response to the disturbance as experienced/perceived by others).

Before administering drug treatment for disturbed behaviour, a multidisciplinary team should assess the person's condition, try to identify underlying causes and contributing factors and define the specific purpose of drug treatment if decided upon. All those treating the person should consider other management methods not involving drugs.

Regular medical monitoring should occur, and all those directly involved in the adult's care (including the person him/herself, family, guardians and other carers etc.) should be informed of the reason for the prescription, the risk and signs of side effects, what to look out for and signs of its success. Staff and other carers should have easy access to a doctor in case of concern.

As much disturbed behaviour is intermittent rather than constant, the long-term prescription of drugs for it should be avoided. On the contrary, staff should be taught how to recognise the preliminary signs and de-fuse the situation or find a diversion for the adult. In addition, they should be made aware of the possibility that certain tranquillisers and sedatives can actually lead to an increase in restlessness.

Psychological restraint

Definition: The use of verbal and/or non-verbal behaviour to restrict the adult's liberty of movement (e.g. threats, humiliation, emotional blackmail, specific reactions or gestures etc.)

Psychological restraint may sometimes be hard to identify, as it may be dependent on knowledge of the adult's character, which may not be obvious to outsiders. For example, no-one should be forced to wear or not wear a certain attire, as some people may find it degrading and humiliating to wear certain clothing such as pyjamas outside the confines of the home and this could lead them to stay in their room. Similarly, the threat of a particular action (regardless of whether it would ever be carried out), should the adult leave a room, boundary, bed or chair, may be sufficient to prevent him/her from doing so.

Staff and carers should be made aware of the need to respect the rights and dignity of the adult at all times. They should also bear in mind how the adult might perceive their behaviour towards him/her, particularly in view of the potential unequal distribution of power and the adult's possible perception of this.

Appendix 2

Advance Directive (living will)

Should the following three conditions apply:

1. I have a form of dementia (or another disorder) for which there is no cure and/or likelihood of improvement;
2. My mental functions have become severely and permanently impaired;
3. I am consequently unable to understand and make decisions for myself concerning my care and/or medical treatment.

my wishes are as follows.

SECTION A : GENERAL CARE AND TREATMENT ISSUES

Appointment of a guardian

I would like a guardian to be appointed to make care and treatment decisions on my behalf.

I would like the following person to be my guardian (if s/he is able and willing to do so). Name and telephone number and/or address:

Place of care and/or treatment

Regardless of whether a guardian is appointed, I would like the following wishes to be respected:

I want to go into residential care, if I can no longer live independently at home.

I want to be allowed to stay in my own home for as long as possible. I want the necessary steps to be taken to make this possible.

I want to go to an appropriate day care centre, should my condition necessitate this.

Other remarks concerning section A:

SECTION B: PARTICIPATION IN RESEARCH AND DRUG TRIALS

- I want to take part in medical research or a clinical drug trial, provided that it is likely to entail personal benefit.
- I agree to take part in medical research or a clinical drug trial, even if it is unlikely that I will personally benefit from such research.
- I agree to take part in medical research or a clinical drug trial, even if it is unlikely to entail personal benefit, provided that other people with a similar medical condition and/or of the same age group are likely to benefit from it.
- I agree to take part in other forms of research (e.g. psychological, observational, statistical etc.).
- In addition to the usual requirements to safeguard my dignity, safety and wellbeing, I want my clear request to withdraw from the research (regardless of the level of my incapacity) or that of my guardian (made on my behalf) to be respected.

SECTION C: ORGAN DONATION

- Should the situation ever arise that a close family member is in need of an organ or tissue donation, I consent to donate regenerative organs/tissue.
- Should the situation ever arise that a close family member is in need of an organ or tissue donation, I consent to donate non-regenerative organs/tissue.
- In addition to close family members, I also consent to donate non-regenerative and/or regenerative organs/tissue to the following person(s), should the need ever arise:

- I consent to donate all or the following parts of my body for the purposes of medical research after my death:

Other remarks concerning section B or section C:

SECTION D: END OF LIFE DECISIONS

Concerning my physical condition

If my physical condition becomes so bad that it would be necessary for me to receive medical treatment to keep me alive:

- I want to be kept alive for *as long as possible*, using whatever forms of medical treatment are available.
- I want to be kept alive for *as long as is reasonably possible*, using whatever forms of medical treatment are available. Consequently, I refuse any medical treatment that is harsh or painful, if such treatment would merely serve to prolong the process of dying and/or my sufferance.
- I do not want to be kept alive by medical treatment and therefore refuse any medical treatment.
- If I fall into a state of unconsciousness (e.g. coma or cardiac arrest), I do not want to be resuscitated.
- I would like to allow doctors a certain degree of discretion to act in my best interests, if since this advance directive was written or confirmed, medical advances have been made (which I may have been unaware of), which cast doubt on what my wishes would have been.

Concerning the alleviation of my suffering

- I want to receive palliative care to ease my suffering (physical, spiritual and mental).
 - I want to receive sufficient medication to keep me free from pain even if this entails a risk of shortening my life.
 - I want to be given the possibility to die with dignity and in peace.
 - I want to die, if possible, in the company of my family and/or close friends.
 - I want to die, if possible, at home.
 - I want to receive a visit from someone sharing my spiritual/religious beliefs, i.e.
-

Other remarks concerning section D:

SECTION E: OTHER WISHES

PERSONAL DETAILS:

Name : _____

Date of birth: _____

Address: _____

Telephone number: _____

Date, place and signature: _____

Number of sheets attached: _____

Renewal/confirmation:

Date, place and signature: _____

Date, place and signature: _____

Date, place and signature: _____