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Alzheimer Europe Report

End-of-life care for people with dementia



***Alzheimer
Europe Report
(2/2008)***

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Table of contents

1	Preface	7
2	Executive Summary/Recommendations	9
3	Alzheimer Europe's position and guidelines on end-of-life care	15
3.1	<i>Introduction</i>	15
3.2	<i>Clarification of terms</i>	16
3.2.1	<i>Carers and healthcare professionals</i>	16
3.2.2	<i>End-of-life and dying</i>	16
3.2.3	<i>End-of-life care</i>	16
3.2.4	<i>Palliative care</i>	18
3.3	<i>Guiding principles</i>	19
3.4	<i>General guidelines</i>	21
3.4.1	<i>Dignity and quality of life</i>	21
3.4.2	<i>Mild and moderate dementia</i>	22
3.4.3	<i>Advance planning</i>	23
3.4.4	<i>Carers' needs</i>	25
3.4.5	<i>Interaction between carers and healthcare professionals</i>	27
3.4.6	<i>Where care is provided and the kind of support needed</i>	28
3.4.7	<i>The social and built environment</i>	30
3.4.8	<i>Enhancing emotional and personal well-being</i>	31
3.4.9	<i>Communication</i>	32
3.4.10	<i>Spiritual care</i>	33
3.4.11	<i>Cultural issues and minority groups</i>	35
3.5	<i>Guidelines on specific care issues</i>	36
3.5.1	<i>Pain management</i>	36
3.5.2	<i>Feeding and swallowing problems</i>	39
3.5.3	<i>Constipation, diarrhoea and incontinence</i>	41
3.5.4	<i>Pneumonia and infections</i>	42
3.5.5	<i>Dehydration and mouth care</i>	43
3.5.6	<i>Skin care</i>	43
3.5.7	<i>Body temperature</i>	45
3.5.8	<i>Sedation</i>	45
3.5.9	<i>Restraint and falls</i>	46
3.5.10	<i>Difficulty breathing and "the death rattle"</i>	47
3.5.11	<i>The moments preceding and following death</i>	48
3.6	<i>Annex: A brief consideration of a few ethical issues</i>	50
3.6.1	<i>Personhood</i>	51
3.6.2	<i>Autonomy and capacity</i>	51
3.6.3	<i>Beneficence and non-maleficence</i>	52
3.6.4	<i>Justice/equity</i>	53
3.6.5	<i>Cultural issues linked to principles of bioethics</i>	53
3.6.6	<i>Withholding and withdrawing treatment</i>	55
3.6.7	<i>Futile or over-zealous treatment</i>	55
3.6.8	<i>Doctors' dilemma to preserve life but also respect patients' wishes</i>	56
3.6.9	<i>Discrepancy between current and former wishes</i>	57
3.6.10	<i>Research</i>	57
3.6.11	<i>Euthanasia and assisted suicide</i>	58
4	Acknowledgements	61
5	Bibliography	63



Preface

1 Preface

In 2007, on the occasion of its Annual Conference in Estoril (Portugal), Alzheimer Europe set up a working group to investigate the end-of-life care of people dying with or from dementia. I was invited to chair this working group, a responsibility which I gladly accepted.

The members of the working group came from a wide range of professional backgrounds such as palliative care, old age psychiatry, psychology, medicine and nursing. Some had personal experience of caring for a person with dementia in the final stage of life. In addition to the various knowledge and experience that people brought to the working group, the fact that they also came from a range of different countries with different cultural and historical backgrounds led to a great deal of discussion about certain issues. I feel that this has resulted in a very comprehensive document which combines theoretical and philosophical arguments with very practical and straightforward advice, including, where necessary, information about the medical aspects of end-of-life care.

The document is addressed to everyone with an interest in providing good quality end-of-life to people who have dementia, not just those with end-stage dementia but also people in the earlier stage of dementia who may have another terminal condition. We have tried to emphasize the importance of involving people with dementia and their carers in the whole care process.

Many of the recommendations contained in the report are dependent on an effective financing, organisation and co-ordination of end-of-life care, including multi-disciplinary trained professionals and appropriate care facilities in all geographical areas. For this reason, our executive summary contains concrete recommendations for policy makers which highlight the main areas where improvement is needed.

I would like to thank Dianne Gove, the information officer of Alzheimer Europe, for her work in carrying out an extensive literature review, preparing the various drafts of the document and incorporating the comments and advice provided by the members of the working group. I would of course also like to thank the members of the working group (Ana Bernardo, Mary Cosgrave, Iva Holmerová, Sabine Jansen, Birgitta Martensson, Barbara Pointon and Catalina Tudose, and) for their dedication and the very active role they played in sharing their vast expertise, experience and ideas. Last but not least, I would like to thank the following who also commented on the final draft: Jennifer Abbey, António Oliveira Costa, Jenny Henderson, Annemarie Kesselring, Lukas Radbruch, Elisabeth Reitingner, Charles Scerri and Maria Rosário Zincke dos Reis.

I hope that this document contributes towards the development of a positive approach to the care of people with dementia who are dying and to greater support of those involved in their care.

Sigurd Sparr
Honorary Secretary
Alzheimer Europe



***Executive Summary/
Recommendations***

2 *Executive Summary/Recommendations*

The present paper constitutes the input of Alzheimer Europe and its national member organisations to the ongoing discussions within Europe about end-of-life care for people with dementia including the appropriate support of carers. It is the result of discussions carried out in a multidisciplinary group composed of experts in the field of palliative care, medicine, psychiatry and psychology, as well as carers, in collaboration with the board of Alzheimer Europe and its member associations.

The following sets of statements and recommendations are extracted from the full guidelines, which include recommendations and our position on various care-related issues, and can be found in section II of this document. A brief consideration of some of the ethical issues linked to the good care of people dying with/from dementia can be found in Annex I.

People with dementia

1. The dignity of the person with dementia should be respected at all times.
2. Alzheimer Europe is of the opinion that a palliative care approach should be adopted for people with end-stage dementia as attempts to cure and prolong life are inappropriate for them. We nevertheless respect the right to individual choice.
3. The aim of treatment and care should be to maximise the quality of life and level of comfort of the person with dementia and not to prolong the life.
4. It should be provided if and when needs arise and before the situation become unmanageable.
5. Consequently, futile and harsh or invasive treatment, in fact any treatment with no prospect of improving quality of life, should be avoided.
6. Preference for place of care, where it is known, should be respected, but in all cases the choice of care setting should take into account the best current interests and needs of the patient and carer. Their wishes, including those expressed in advance, should be followed wherever possible.
7. The person with dementia should be consulted and kept informed about care and treatment issues to the greatest extent possible.
8. There should be no discrimination against people with dementia in terms of treatment, care or attitude e.g. because of their disease or on the basis of age, gender, cultural identity, language, sexual orientation or economic status.

Carers

9. Carers should be provided with practical support as well as emotional, spiritual and psychological support.
10. They should be entitled to an assessment of their health and psychosocial needs leading to a care/support plan. Such assessments and adaptation of the care plan may need to be repeated regularly.
11. With regard to grief and mourning, which may have a delayed onset, the provision of support should, if necessary, extend beyond the death of the person with dementia.
12. Carers should be consulted and involved in the care of the person with dementia provided that they are able and willing to do so.
13. Carers should be informed and reassured about possible symptoms which may occur and about the possible consequences of any decisions they may make about treatment and care.
14. Carers should be provided with specific training.
15. Carers should be consulted about options for anti-dementia drugs.

Healthcare professionals

16. Dementia should be an obligatory undergraduate component of doctors' training. Training in dementia care should also be a component part of training courses in nursing and of continued further education in the medical profession.
17. Other healthcare professionals, non-medical professional carers and palliative care volunteers should also receive appropriate training in dementia care and communicating with people with dementia.
18. Additional training/discussions should focus on the ethical issues involved in palliative care for people with dementia as well as other difficult issues such as breaking bad news, communicating with the person with dementia, surrogate decision-making and discussing the prognosis and difficult treatment options with carers.
19. Mobile palliative/geriatric/psychogeriatric care teams should be set up in order to provide assistance and advice in people's homes and in residential care settings.
20. Every effort should be made to ensure continuity of staff.
21. All health care professionals and volunteers working with people dying with dementia should be provided with support if needed.
22. A dementia care coordinator/advisor should be appointed for every person dying with/from dementia irrespective of the stage of the disease and of where care is provided.

23. The dementia care coordinator/advisor should ensure that the various health care professionals are aware of the global needs of the person with dementia, keep them updated on how those needs are being met and inform them of changes in the person's condition. Such coordination should ideally be extended to other non-medical or paramedical professionals such as occupational therapists, religious and spiritual counsellors, therapists, social workers and dietitians. An alternative system would be an integrated care pathway¹.
24. A key/assigned care worker should be appointed for every resident with dementia in a nursing home or residential care institution (with a stand-in so as to allow for holidays and sickness).
25. Nursing homes and residential care institutions should employ specialists in dementia care.
26. As most carers have in-depth knowledge of the person with dementia, are aware of his/her preferences and are experienced in communicating with him/her in a meaningful way, professional carers should consult them and try to involve them in the care process.
27. If possible, a key contact person² should be appointed from amongst the carers, relatives and close friends of the person with dementia to act as the main communication partner with the professional care team.
28. Professional carers should, as far as possible, involve carers in care decisions and attend to the physical and mental well-being of carers.
29. Professional carers should help carers to understand the progression of dementia in the final stage and the implications of any decisions they may be asked to make with regard to intervention or non-intervention linked to care.
30. More research should be carried out into the identification of the signs of imminent death in people with dementia so as to ensure that appropriate treatment decisions are made and that appropriate support is provided to people with dementia and carers.
31. Attempts should be made at the time of admission or failing this shortly after to ascertain the preferences, values, beliefs and wishes of the person with dementia in relation to various care issues.
32. Healthcare professionals should respect the beliefs, values and practices of people with dementia and carers from different cultures and minority groups.
33. Healthcare professionals should be trained in the management of pain, be experienced in the use of relevant pain assessment tools and be extra vigilant for signs of pain in people with dementia.
34. The WHO three-step ladder for treating pain in cancer patients should be adapted for the treatment of pain in end-stage dementia.

¹ Please see http://www.mcpcil.org.uk/Liverpool_care_pathway for example.

² In some countries, this person could be a legally appointed health care proxy, welfare attorney or "personne de confiance" (trusted person).

35. Pain detection scales should be refined so as to be more suitable for people with dementia and to distinguish more effectively between pain and discomfort or distress.
36. Tubes and PEGs for artificial hydration and feeding should not normally be indicated for people with end-stage dementia.
37. Unnecessary sedation should be avoided.
38. Mechanical restraint should only be used in very exceptional circumstances and if used, it should be recorded and monitored, and constant surveillance should be provided³.
39. Doses of medication should be reduced in accordance with the development and severity of the disease and/or weight loss.
40. Measures should be taken to prevent falls whilst the person with dementia is mobile and even when he/she has lost mobility as it is possible to fall from chairs and beds.

Policy makers/the State

41. End-stage dementia should, when appropriate, be recognised as a terminal condition requiring palliative care.
42. People with end-stage dementia should be guaranteed access to palliative care/geriatric services.
43. It should be borne in mind that many people dying from cancer, respiratory disease or heart failure will also have a co-morbidity of dementia which will complicate the provision of other specialist care.
44. Palliative care services and facilities should be provided to people dying with/ from dementia (irrespective of whether they have another terminal illness). These services need to be affordable to people with dementia and carers.
45. More public healthcare funds should be allocated for the care of people with dementia. This should include financial support for palliative care networks.
46. Palliative care services in the home and in hospitals or residential care settings should be developed and/or improved.
47. Free information on the availability of services and entitlement as well as guidance on how to apply for palliative care support should be available.
48. Governments which do not have a system where anti-dementia drugs are reimbursed by the health authorities should be encouraged to develop such a system.
49. Legislation covering access to palliative care services should take into account the nature of dementia and the progression of the disease.

³ Please also refer to the Mental Welfare Commission for Scotland's guidelines on the use of restraint ("Freedom, restriction and restraint") at: http://www.mwscot.org.uk/newpublications/good_practice_guidance.asp

50. Carers should have access to free respite care in the home to enable them to continue caring for the person with dementia and in recognition of their valuable role and work.
51. Measures should be taken to enable carers to coordinate their working lives with the task of caring. This should include measures to promote flexible working hours and/or paid leave to care for the person with dementia at the end of his/her life, as well as measures to protect their pension rights.
52. Volunteers and volunteer associations providing palliative care support should be encouraged, supported and if necessary trained in dementia.
53. A framework and standards for training should be developed in order to ensure that there is a sufficient number healthcare professionals who are trained in palliative care for people with dementia.
54. It should be ensured that the financial remuneration and working conditions of healthcare professionals working in the field of palliative care of people with dementia are sufficiently rewarding so as to reflect the value of the work carried out in this domain.
55. Research into palliative care for people with dementia should be promoted.



*Alzheimer Europe's
position and guidelines
on end-of-life care*

3 Alzheimer Europe's position and guidelines on end-of-life care

3.1 Introduction

A recent survey, carried out by Alzheimer Europe in the framework of its 3-year, European Commission-funded EuroCoDe project, revealed a lack of palliative care services for people with dementia in Europe as well as a lack of support for carers who care for people with dementia at home in the final stage of life. Whilst limited support at home exists in a few countries, the vast majority of places in palliative care centres are occupied by people with cancer. This is perhaps partly due to the fact that the number of places in such centres is limited and also because dementia is not always recognised as a terminal illness requiring specialist care so people with dementia are simply not referred to such centres. Another possible reason for the shortage of places for people with dementia is that palliative care unit staff often lack training in dealing with people with dementia. Consequently, they may find it difficult to deal with certain behaviour and to balance this with respecting the needs of other residents. Nevertheless, people with dementia in need of residential palliative care should have the same opportunity as everybody else. In addition, public awareness of the palliative care needs of non-cancer patients and especially patients with dementia must be improved by means of medical education and awareness raising campaigns.

However, people with dementia in the last stages often need round the clock care and may have needs which require specialist attention. In many cases, care can nevertheless be provided at home but this can be physically and mentally exhausting for carers, many of whom are elderly people who may have their own health problems.

Having investigated the kind of palliative care support available to people with dementia and carers in Europe, Alzheimer Europe set up a working group in 2007 to look at the practical issues linked to the good care of people dying with/from dementia (at any stage of dementia, at any age and irrespective of whether they have co-morbid conditions).

This working group was chaired by Sigurd Sparr from the Norwegian Alzheimer Association (who is also the Honorary Secretary of Alzheimer Europe) with members from the Czech Republic, Germany, Ireland, Luxembourg, Portugal, Romania, Switzerland and the United Kingdom with further input from Australia. Details of the members of the working group can be found in section III of this document.

The group wanted to consider the kind of end-of-life care that was most appropriate for people with dementia and to emphasise what makes end-of-life care for people with dementia different from that provided to people with other terminal illness i.e. to highlight the special needs and problems faced by people with demen-

tia, professionals and carers due to the specific nature of the disease. Whilst this paper is somewhat biased in favour of a palliative care approach, for reasons which will be explained later, Alzheimer Europe nevertheless respects the rights of people with dementia and their carers to choose a different approach.

3.2 Clarification of terms

Some of the terms used in this document are used differently elsewhere. For this reason, we would like to explain our use of the terms “carer”, “healthcare professional”, “end-of-life and dying”, “end-of life care”, “palliative care” and “quality of life”.

3.2.1 Carers and healthcare professionals

The term “carer” is used to refer to someone who cares for a person with dementia on an informal and unpaid basis usually at home (although in some countries, carers may be granted a legal status and some may receive allowances from the State when providing care at home). In most cases, the carer is a relative or close friend. The kind of care provided depends on each person’s situation but typically involves help with physical care, practical issues and safety, as well as emotional and psychological support. Once the person is in long-term care, the emphasis of this role shifts but the burden of caring remains. It may still involve some degree of practical care but perhaps with a greater emphasis on advocacy, managing financial affairs and providing support and conversation (Woods et al., 2007).

When referring to people who provide professional care to people with dementia, the global term “healthcare professional” is used, or in some places a specific job title such as doctor or nurse. The term “doctor” is used to refer to a person who is legally qualified in and a licensed practitioner of medicine i.e. a physician, medical practitioner or medical doctor. It should not be confused with holders of other academic doctorates.

3.2.2 End-of-life and dying

The end-of-life, in the case of dementia, is sometimes referred to as “terminal dementia” or “end-stage dementia”. It is difficult to estimate when the end of life and the process of dying actually begin, especially in the case of dementia. It could, for example, be argued that the process of dying begins when brain cells start to be destroyed and could therefore cover a fairly lengthy period of time. In oncology, the palliative care phase may be 6 months or even longer. In the later stages of dementia, people may have several near-death experiences⁴.

People with dementia who are dying are not all in the final stages of dementia⁵. The cause of death of people with dementia differs from one person to the next. This is because each person is different, the disease process is different and there may be co-existing conditions such as diabetes, cancer or cardiovascular disease. There are

⁴ Lynn J, Adamson DM Living well at the end of life, adapting health care to serious chronic illness in old age. Washington: Illness Trajectories and palliative care BMJ (clinical Research ed) 2005;330:7898-1007-10011.

⁵ Please also see section on “mild and moderate dementia”.

also other conditions such as the AIDS Dementia Complex, Parkinson's disease and Huntington's disease which are linked to dementia and Alzheimer's disease is quite common in adults with Down's Syndrome.

In fact, dementia is not always recognised as a terminal condition or explicitly referred to as the actual cause of death, at least not as the main cause of death. For example, the health conditions covered in Eurostat's (2007) statistics on causes of death include cancer, ischaemic heart disease, pneumonia, chronic liver disease, diseases of the central nervous system, diabetes mellitus, AIDS, alcoholic abuse and drugs dependency. Similarly, the WHO 2004 report on "Better Palliative Care for Older People" cites a study which predicts the five main causes of death for 2020 as being ischaemic heart disease, cerebrovascular disease, chronic obstructive pulmonary disease, lower respiratory infections and lung, trachea and bronchial cancer. Moreover, a British study found clear evidence of the underreporting of dementia on death certificates (Morgan and Clarke, 1995). The lack of a specific reference to dementia when predicting or recording cause of death hides the impact of this disease.

Nevertheless, Cox and Cook (2007) identify three distinct groups of people with dementia in need of end-of-life care. These are:

- People who reach the end of life but die from some other identifiable condition, such as cancer, before reaching the final stage of dementia.
- People who reach the end of life with a complex mix of mental and physical problems but where the effect on brain functioning is not as advanced.
- People who reach the end of life and die of the complications of dementia, such as end-stage dementia.

People could therefore be described as dying from dementia or dying with dementia.

This document addresses the end-of-life care needs of people with dementia in any of the above-mentioned groups i.e. anybody who at the moment of death had dementia. However, some of the information and recommendations may be more relevant in the case of end-stage dementia.

For the purpose of this document, the working group identified the end of life as being a matter of days or weeks before the actual moment of death.

3.2.3 End-of-life care

End-of-life care is the term used to describe care provided in the period shortly before death. Ideally, it is a continuation of good care provided over the long trajectory of the disease.

Some people might want access to all possible treatment options including those which are generally considered invasive or aggressive, whereas others might opt for a palliative approach. This should normally depend on the wishes of the patient (if he/she is able to express them or alternatively, if he/she wrote an advance directive). In some cases, this may unfortunately depend on the availability of suitably trained staff, the availability of appropriate facilities, the financial situation of the patient and on his/her competence to decide or express his/her wishes.

3.2.4 Palliative care

Palliative care covers the period from diagnosis of a non-curative illness to death (for the terminally ill person) and beyond (for family and close friends). This may differ considerably from one disease to the next and from one person to the next. As pointed out by the Finnish National Advisory Board on Health Care Ethics (2003), “Palliative care is not bound to the closeness of death and can last up to several years depending on the illness.” This is certainly the case for dementia and we are in no way suggesting that a palliative care approach should only be adopted in the last moments of life. In fact, the provision of palliative care should ideally be introduced in a seamless manner, overlapping and complementing good dementia care. However, we will limit our use of the term “palliative care” to that provided at the very end of life i.e. in the last days and weeks of life as this is the scope of this paper.

There are a few misunderstandings surrounding palliative care such as the belief that it simply consists of withdrawing all forms of treatment and accompanying the dying person, that it is only used when every other form of treatment has failed or that it is limited to the prescription of opiates (strong analgesics/“painkillers”). This is clearly not the case. On the contrary, therapeutic measures and palliative care often complement each other and cannot be considered in complete isolation from one another (Swiss Academy of Medical Sciences, 2006).

The working group agreed on the following definition of palliative care, which is adapted from and closely resembles that developed by the World Health Organisation in 2002.

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- does not aim to prolong life;
- strives for a good death (the least distressing passage partly due to the relief of suffering from pain and other distressing symptoms);
- may however be used in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications;
- integrates the psychological, religious and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- aims to enhance the quality of life of patients;
- offers a support system to help family and friends cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- is an attitude, a philosophy and a method which should be possible in any environment.

Moreover, it must also be borne in mind that some people would prefer to receive every possible form of treatment available that might keep them alive even if burdensome to them. This should not prevent them from receiving the same care and attention as that provided to people receiving palliative care at the end of their lives i.e. the assessment and treatment of pain and other problems, physical, psychosocial and spiritual, as well as support to family and close friends before, during and after their death, but it would perhaps be better described as “end-of-life care”.

In this document, the term palliative care is used to refer to palliative care only at the end of life unless stated otherwise. The term end-of-life care is used to refer to care at the end of the life of the person with dementia, irrespective of whether a palliative care approach has been adopted.

Whilst respecting the right to individual choice, Alzheimer Europe is of the opinion that attempts to cure and to prolong life are inappropriate for people with end-stage dementia and that a palliative care model should be adopted.

3.3 Guiding principles

The working group acknowledges the value and relevance of the Council of Europe's “Recommendation Rec(2003)24 of the Committee of Ministers to Member States on the organisation of palliative care” as well as Alzheimer Europe's recommendations

on the legal rights and protection of adults with incapacity (2000) and Alzheimer Europe's position on advance directives (2004). Examples of relevant articles from Alzheimer Europe's legal recommendations include the following:

- The autonomy of the person with dementia should be respected at all times. As long as s/he maintains the ability to make decisions concerning his/her life, such decisions should be sought, respected and given priority over any proxy decision-maker. Indeed, irrespective of the level of capacity of the person with dementia, his/her interests must always come first. There should always be an assumption in favour of capacity and of involvement and choice. (§7)
- Alzheimer Europe has written an advance directive which is available in all the official languages of the European Union⁶. We recommend, however, that people seek guidance from a doctor in order to ensure that the advance directive is clear and in line with modern practice. It is also necessary to ensure that the person writing the advance directive is aware of the consequences of his/her choices and that s/he has sufficient capacity to write such a document. In order to ensure that advance directives are respected, we recommend that legal representatives and medical professionals be obliged to take into consideration wishes expressed in such documents. Failure to do so should require valid justification. Furthermore, we recommend the setting up of a national register of advance directives, the creation of co-operation between countries and the inclusion of details about the advance directive in existing computerised medical files (subject to respect for national laws on data protection). (§9)
- It is important to ensure that at all stages, as well as when the person with dementia approaches the end of his/her life, his/her rights are respected and his/her dignity maintained. Certain decisions which need to be taken at the end of a person's life cannot be easily taken by someone else e.g. concerning resuscitation, life-prolonging treatment, the use of certain forms of harsh or invasive treatment or painkillers and the provision of palliative care. Such decisions should therefore ideally be noted in an advance directive. This should be clearly recorded in the person's medical file. (§19)

Examples of relevant articles from Alzheimer Europe's position on advance directives include the following:

- A person with dementia remains a full person regardless of the severity of the disease or the degree of cognitive decline. Alzheimer Europe does not adhere to any theory which denies people with dementia "personhood" i.e. which implies or states that a person lacking capacity is in some way not a person. The person with dementia should always be treated with respect and consideration.
- The autonomy of the person with dementia should be respected at all times, although other principles such as beneficence, justice and non-maleficence should also be borne in mind and balanced with respect for the person's right to self-determination.

⁶ The advance directive is available in the official languages of the European Union before enlargement i.e. Danish, Dutch, English, Finnish, French, German, Greek, Italian, Portuguese, Spanish and Swedish, as well as in Czech.

- Capacity is not an all-or-none phenomenon. We believe that it should always be considered and assessed in relation to specific decisions or categories of decision (the person is deemed capable or incapable of decision A or decision B, etc.). In addition, capacity can be partial. In dementia a person does not usually suddenly lose the capacity to decide about something, but gradually loses it. In many forms of dementia, furthermore, a person's capacity to make certain decisions may fluctuate with time. For all these reasons, capacity should be assessed on a case-by-case basis, in relation to specific areas of decision-making, and taking into account the overall condition of the person.
- It must be recognised that many legal provisions on proxy decision-making, whether by guardians, courts or other means, have traditionally depended on an all-or-none view of capacity, though new laws in a number of countries are attempting to provide a more flexible and graduated approach to incapacity.

3.4 General guidelines

3.4.1 Dignity and quality of life

There are so many issues to consider when planning or providing end-of-life care to people with dementia but underlying most is the importance of respecting the dignity of the person with dementia and trying to provide the best quality of life possible.

People's opinions as to what is dignified and undignified differ. Something that is considered undignified to one person may be fully acceptable to another. Werth et al. (2002) describe issues of dignity as a function of a person's culture and unique value system which may also change over time.

Holmerová et al. (2007) provide an overview of how dignity is perceived in specific relation to people with dementia who are dying. They explain that dignity is often understood as being linked to autonomy and self-control, some degree of control over the process of dying, and the way that individuals are viewed by others as well as by themselves. They refer to the concept of "Menschenwürde", a German term which refers to the undeniable value of human beings regardless of their social, mental or physical properties, but point out that people often find it easier to define what constitutes a violation of dignity e.g. not being treated with respect or understanding, feeling a burden to others or being subjected to abusive or humiliating behaviour. Indeed, it is often the fear of loss of dignity which makes the prospect of living with dementia so daunting.

Quality of life is extremely important in end-of-life care, particularly palliative care where one of the aims is to enhance quality of life. However, as with the concept of dignity, this is very subjective and it is difficult to determine what quality of life means for another person, especially when that person has difficulties communicating. Quality of life assessments may be linked to various decisions that need to

be made e.g. about the place of care, degree of contact, comfort and the avoidance of pain. But a consideration of what makes life worthwhile and agreeable to the person with dementia should be considered for every aspect of care.

In some cases, assessments about quality of life may have consequences on whether a person lives or dies e.g. when doctors need to decide whether to resuscitate a person or withhold treatment. Assessments about quality of life can be influenced by personal views and even generalisations or incorrect assumptions about people with dementia, incapacity and/or elderly people. Moreover, it could be argued that doctors do not have the relevant training and expertise to make decisions about the quality of life of their patients. For these reasons, it is important to consult carers and the various members of the care team when making such assessments (i.e. on medical and non-medical issues linked to quality of life) and to consult any relevant documentation such as advance directives and statements of values (please see next section for details).

Measures should be taken, irrespective of the care setting, to preserve, enhance and if necessary restore the dignity of the person with dementia.

Such measures might include:

- Encouraging independence, choice and control.
- Getting to know the person with dementia and his/her needs in order to provide personalised and appropriate care.
- Respecting his/her individuality and personhood.
- Showing kindness, respect and compassion to the person with dementia and his/her relatives and close friends.
- Maintaining a dialogue and some form of human contact even when it is no longer possible to communicate verbally.
- Discussing with the person with dementia if possible and with his/her carers about care issues linked to dignity.
- Reviewing decisions and practice on a regular basis.

When assessing the quality of life of people with dementia, carers and members of the care team should be consulted as well as any documents which might contribute towards a better understanding of the feelings and views of the person with dementia on this issue.

3.4.2 Mild and moderate dementia

Many elderly people who are dying also have dementia which may or may not have been diagnosed. Whilst dementia is more common in elderly people, some younger people may have dementia at the end of their lives (e.g. people with Down's Syndrome or the AIDS dementia complex). However, most people with dementia have

not reached the end-stage by the time of their death. This means that most people with dementia in need of end-of-life care have more moderate forms of dementia.

People with mild to moderate dementia may be better able to communicate their wishes, have more decision-making capacity and be more mobile than those with end-stage dementia. However, there is a risk that carers and healthcare professionals might overlook or underestimate their care needs, particularly if dementia has not been diagnosed. This might, for example, involve failure to ensure that they take their medication (perhaps prescribed for comorbid conditions, the symptomatic treatment of Alzheimer's disease or to keep the blood thin in the case of vascular dementia), insufficient attention to eating and swallowing difficulties and overlooking communication difficulties thereby resulting in misunderstandings, non-compliance with care and treatment, "challenging behaviour" and failure to obtain valid consent.

Healthcare professionals and even home care workers should be aware that people receiving end-of-life care might also have dementia.

Those providing care in the home should be vigilant for signs of dementia in a person receiving end-of-life care.

Even if a clinical diagnosis of dementia has not been made, carers should be provided with appropriate support and services in keeping with an assessment of the needs of the person with dementia.

3.4.3 Advance planning

In its position paper on advance directives (Alzheimer Europe, 2006), Alzheimer Europe encourages advance planning in the context of dementia care, which may or may not lead to the writing of an advance directive. Advance planning can be seen as a global approach to future health care and welfare involving reflection, discussion and communication of treatment and care preferences throughout the course of the disease and also at the end of life. This could also include a discussion about practical issues such as future visits, as well as about spiritual beliefs, fears of suffering and dying and even funeral arrangements. Advance directives must be written at a time when the person with dementia still has sufficient capacity to do so. For this reason, advance planning needs to take place long before the person reaches end-stage dementia.

Some people do not want to address issues surrounding end-of-life care and prefer to let others decide on their behalf i.e. relatives, friends and healthcare professionals. In some countries, it is possible for a person with sufficient capacity to grant a power of attorney and/or appoint a healthcare proxy. A health care proxy can generally make treatment decisions in a setting or in circumstances which were not previously considered by the person with dementia, whereas an advance directive tends to be linked to specific named treatments or situations and risks being too vague or too specific. In situations where it is unclear from an advance directive

what the author actually wanted, a health care proxy may be asked to interpret the author's wishes as greater confidence is often placed in the judgment of a designated person than in a living will.

In some cases wishes will change. Moreover, people with dementia who write an advance directive in an early stage may not take into account that their wishes may change with the course of the disease. So everybody who is involved in the care should look out for signs of actual wishes even if they cannot be expressed verbally.

On the other hand, it should be noted that surrogate decision makers do not always represent the wishes of the person they are representing. Several studies have shown that proxies and patients' decisions often differ (Reilly, 1994). Surrogate decision makers have their own preferences, priorities, values and beliefs which may influence the decisions they make. They may also experience emotional conflict and pressure from relatives and close friends. To make matters worse, people who appoint a health care proxy or let others decide on their behalf, do not always discuss their health care preferences with them in advance.

An alternative to advance directives and substitute decision makers is a statement of values. This is not a legal document but rather a statement about what is important to a person in his/her life e.g. values, beliefs, attitudes, preferences, dislikes and habits. This kind of information can help professional carers to understand something about the personal world of the person with dementia even when he/she has difficulty communicating and can be especially useful for people with dementia who have no family. It can be useful to surrogate decision makers and healthcare professionals in general.

People with dementia who are in the last stage of life are likely to have difficulty expressing their wishes. If there is no advance directive or official surrogate decision maker, carers should be encouraged to discuss end-of-life care issues in advance with healthcare professionals. This would prevent them having to make difficult decisions with ethical implications at a time when they are likely to be under great emotional strain. Whenever decisions are made on behalf of a person with dementia, relatives and close friends should be consulted and the decisions made within a multidisciplinary team, also taking into account various bioethical and legal issues.

People should be encouraged to involve their doctors, close family and friends in discussions linked to advance care planning.

Healthcare professionals should develop the necessary skills to enable them to sensitively discuss advance care planning.

Nobody should be put under pressure to write an advance directive.

Carers should be asked to provide healthcare professionals with a copy of any advance directive or other form of advance planning.

Even if not legally binding, such documents should serve as information about the wishes of the person with dementia.

Some people with dementia, or through their families, may have made their wishes known that they do not want to be subjected to aggressive treatments (e.g. intravenous lines) to prolong life, apart from subcutaneous medication to relieve terminal pain or distress. It is very important, especially if the patient is transferred from home to hospital, that this wish is respected.

Surrogate decision making should only take place when the person with dementia lacks the necessary capacity for a particular decision.

Capacity should therefore be evaluated on a case-by-case basis.

Healthcare professionals should encourage surrogate decision makers to discuss care issues such as tube feeding and issues surrounding the moment of death well in advance.

There should be safeguards against eccentric or questionable decisions made by surrogate decision makers.

Healthcare professionals should be able to challenge surrogate decision makers if they feel that they are not acting in the best interests of the person with dementia.

3.4.4 Carers' needs

Whilst carers should be provided with support throughout the whole process of caring, this is absolutely essential in the final stage as the person with dementia is likely to need a considerable amount of care and the permanent presence of a carer.

Caring for someone with dementia at home, at any stage but perhaps inevitably more so in the last stage, can be a full-time job. Many carers are elderly people and, as mentioned earlier, may even have their own health problems. Others might have other family commitments such as looking after young children. The kind of support needed will obviously depend on the condition of the person with dementia and the carer's situation but might typically involve assistance with personal care, hygiene, feeding, swallowing, incontinence, keeping the person company and dealing with or avoiding pressure sores (specific medical and care issues are addressed in the next section). Moreover, keeping the person mobile, washing, toileting and/or preventing pressure sores all necessitate moving the person with dementia at various times of the day and night. To do this safely, two people are needed. In addition, carers who are caring for a person with dementia alone need to attend to other matters such as shopping, cooking, cleaning and in some cases paid employment. Continuity of personnel is essential for both people with dementia and carers. A live-in professional careworker would therefore be ideal.

In the absence of adequate support, the physical and mental well-being of carers (caring for a person with dementia at home) is likely to suffer e.g. as a result of physical exhaustion, stress, isolation and lack of sleep, even leading to depression in some cases. Apart from receiving assistance with daily care, it is of utmost importance that carers have the opportunity to take a break from caring. Respite care for the carer is therefore extremely important at this stage, preferably by replacement care at home, because change from a familiar environment becomes increasingly traumatic for people with dementia. Access to home adaptations and assisted technology (e.g. hoisting equipment, stair lifts, special beds, reclining chairs, pressure relieving equipment, monitoring devices etc.) is also important and may enable carers to cope for longer.

Carers are usually relatives but many are same-sex partners, unmarried partners or simply close friends. Legislation and internal rules in healthcare establishments and nursing homes do not always reflect this reality. Moreover, there is a tendency to consider older people as asexual and often an assumption that they are heterosexual (Manthorpe and Price, 2003). Consequently, unmarried couples as well as gay, lesbian, bisexual or transsexual partners, may find themselves excluded from discussions about care and treatment, and even prevented from the same degree of contact with the dying person as that granted to married couples and other relatives.

Of course, not all relatives, partners and friends want to be involved in caring for the person with dementia. Some may feel overwhelmed by the situation or prefer to rely on professional carers. Some might not be on the best of terms with the person with dementia or feel alienated from him/her. It would be a mistake to presume that relationships are always harmonious and caring. All too often, people are just expected to take on the role of carer (especially women i.e. wives, partners, daughters and daughters-in-law) but no one should be “forced” to care. Similarly, men who want to care should not be discouraged by family and/or health care professionals. A survey carried out by Alzheimer Europe (Alzheimer Europe, 2001) into possible gender differences linked to caring for a person with dementia did not find any significant differences between the coping ability of male and female carers.

Carers who are in paid employment may find it increasingly difficult to combine their caring responsibilities with their work, particularly in the end-stage when day care is no longer an option and increased supervision, care and contact are needed. Some countries have special provisions which entitle carers to flexible working hours and paid or unpaid leave to care for a person with a terminal illness. This tends to be for fixed periods of time (e.g. six months), which can be problematic when the end-stage is not accurately predicted. Giving up paid employment to care for a person with dementia not only affects carers’ current financial status but often their pension rights too.

Carers of people with end-stage dementia should be entitled to an assessment of their health and psychosocial needs and provided with the necessary support. Such assessment should be repeated over time and the care plan adopted accordingly.

This should include free respite care and a live-in professional carer.

Home adaptations and the use of assisted technology should be affordable and readily available to anybody caring for a person with dementia who is dying at home.

Healthcare professionals should be encouraged to involve carers in the care process as much as possible provided that this does not run counter to the wishes of the person with dementia.

Assumptions about the desire to be involved or the relationship between the person with dementia and carers should be avoided.

Carers in paid employment should be legally entitled to special provisions to enable them to coordinate more effectively caring and paid employment.

Measures should be taken to ensure that their pension rights are not adversely affected by periods of time spent caring.

3.4.5 Interaction between carers and healthcare professionals

As palliative care also involves looking after the well-being of those close to the person with dementia, it is important that a good relationship is established between carers and healthcare professionals. Carers usually know the person with dementia very well and feel that they are best placed to understand his/her needs and wishes.

When part or all of the care of the person with dementia is taken over by professionals, they may feel excluded and worried that the person with dementia is not being cared for properly. Sharing their knowledge and experience with professional carers can be beneficial for all concerned but for this to be successful a good relationship must be established between the two parties. Carers must feel that their views are taken into consideration, that they can ask questions and that they are allowed to carry out certain agreed tasks linked to the care of the person with dementia. As verbal communication with the person with dementia becomes increasingly difficult, helping with practical care tasks gives carers the opportunity to maintain contact and communicate in another way.

As people with dementia may have several relatives and/or close friends caring for them, it may help professional carers to have one key person whom they can contact for important care-related decisions. Ideally, this person should be chosen by the person with dementia, but this is probably not possible in most cases.

An atmosphere of trust should be developed in which informal carers feel that their views and involvement are appreciated and in which their concerns and even criticisms are dealt with in a positive manner.

Carers should be encouraged to help with the day-to-day care of the person with dementia (if they agree to do so).

Healthcare professionals should ask carers (or the person with dementia if possible) to appoint a key contact person who should then be consulted about care issues.

Because of the range of professionals involved in end-stage care, it would be helpful if a person with dementia and their carer could be allocated one dementia care coordinator/adviser who could give practical advice and coordinate the care.

In a carehome/hospital it is essential that there is a key member of staff who gets to know the resident well and is the main contact for the relative or significant other.

Carers should only be asked to make decisions on behalf of the person with dementia when he/she is unable to do so him/herself.

Attempts should be made to involve and inform the person with dementia as much as possible about decisions being made on his/her behalf.

3.4.6 Where care is provided and the kind of support needed

Most people with dementia spend their last moments of life either at home, in a residential care setting or in a medical or palliative care centre. However, people with dementia do not always state their preferences whilst able to do so (e.g. by means of an advance directive) and often neither they nor their carers have a great deal of choice. Sometimes carers promise to care for the person with dementia at home and then find that they are unable to do so (which can cause guilt feelings). On the other hand, in most countries, residential palliative care (i.e. in a hospice or hospital environment) is not available for the vast majority of people with dementia (Alzheimer Europe, 2007). Consequently, they are often admitted to a general hospital in the last stages. Healthcare staff therefore needs support to see the person with dementia through to the very last stage.

Whilst hospital care at the end of life provides the dying person with assistance from trained medical professionals and the carer with respite, it is often not a good place for someone with dementia to die. It involves being uprooted from everything that is familiar, being placed amongst strangers and sometimes being subjected to unnecessary treatment or simply being left alone to die. This is clearly not comparable to palliative care centres/units or remaining in the home. Moreover, according to Downs (2004), the absence of the carers who know the person with dementia well may be detrimental to effective pain management.

Carers of a person with dementia in a healthcare or residential institution may have the reassurance that the person with dementia is receiving professional care but may feel excluded from the care process and worried that the person might not be receiving good quality care. They may also find it exhausting trying to spend as much time as possible with the person with dementia (who may be at some distance from their own home) and continuously worry about his/her well-being when not present.

As the end draws near, carers may feel the need to be permanently present. Leaving the bedside, even for a short time to recuperate or attend to other matters, may be accompanied by feelings of guilt and fear that the person with dementia will die alone. For this reason, the practice of letting carers sleep at the hospital (or other residential care setting) is very important. Flexible respite care in the home is also essential to ensure that carers get some rest in the secure knowledge that they will be with the person with dementia at the moment of death.

People with dementia should have access to palliative care services at home, in residential care settings and in palliative care centres or units.

Staff in nursing homes with residents who have dementia should be trained in the palliative care approach as well as in dementia care.

Staff in specialised palliative care units should also be trained in the specific needs and requirements of people with dementia.

Measures should be taken to prevent removal of the person with dementia to hospital unless this is absolutely unavoidable.

Irrespective of whether palliative care is provided in a residential care setting, nursing or medical institution, or in the home, people with dementia should benefit from specialised care from a multi-disciplinary team comprised of appropriately and adequately trained staff.

The wishes of the person with dementia should be considered when deciding where palliative care is to be provided along with those of any informal carers directly concerned.

If care is being provided at home, carers should have access to free respite care. This should involve bringing in a substitute carer rather than moving the person with dementia out of his/her home.

Measures should be taken to enable carers to stay with the person with dementia in the period directly preceding death.

3.4.7 The social and built environment

Wherever care is provided, the care environment is important. If cared for at home, the person with dementia is likely to be surrounded by familiar objects whereas in a hospital or residential care setting, this is not necessarily the case. Things which make an environment pleasant and create a feeling of security might include familiar sounds, tastes, smells and objects, a change of view and contact with friends and relatives. This is very important for people with dementia who cannot communicate verbally but whose other senses may be relatively intact. People with Alzheimer's disease often have visuo-spatial problems which can lead to them miscuing their environment. Careful attention to lighting, noise level, furnishings (furniture, curtains and other decorations) and room temperature can also contribute to well-being and reduce the possibility of added confusion.

Even if the person is bed-ridden and relatively unaware of his/her surroundings, the overall comfort and pleasantness of the room is nevertheless important for carers and visitors. A tranquil and pleasant environment is needed which cannot normally be provided in hospitals.

The care environment is also made up of attitudes and behaviour e.g. the use of first names or more formal terms of address, knocking on doors before entering, making people feel important, valued, safe and respected, the appropriate use of humour etc. To a certain extent, such attitudes and behaviour are dependent on individuals but the philosophy and general ethos of a residential or hospital care institution is also a contributing factor. Such issues are also of relevance to home-care workers and healthcare professionals providing home care.

Kitwood (1997) coined the term "malignant social psychology" to describe the way that a lack of attention to the human need for meaningful communication can undermine personhood in the case of people with dementia. He stated:

"The strong word 'malignant' signifies something very harmful, symptomatic of a care environment that is deeply damaging to personhood, possibly even undermining physical well-being."

Examples of malignant social psychology which might be particularly relevant to people with dementia at the end of their lives include disempowerment, infantilisation, withholding, imposition, objectification, labelling, stigmatisation, disparagement, ignoring and mockery.

Attempts should be made to ensure that the care environment is pleasant, and that it provides a sense of security and an atmosphere of normality for each person with dementia.

A person-centred philosophy of care and general ethos should be developed and adhered to by healthcare professionals and homecare workers.

Those who display behaviour and attitudes which are considered damaging to the personhood and/or undermine the physical and psychological well-being of people with dementia in their care should be sanctioned.

3.4.8 Enhancing emotional and personal well-being

The importance of human contact cannot be overemphasised. Even when people with dementia have lost the ability to speak, understand what is being said or recognise familiar faces, they may appreciate human contact i.e. someone sitting next to them, perhaps holding their hand or speaking softly. This may be easier to arrange at home than in a residential care setting where professional carers are often too busy, where such support is not covered by health insurances and/or there may be fears of possible litigation. For this reason, in such settings, visits from family, friends and volunteers are particularly valuable for the well-being of people with dementia. Carers may also benefit from the social contact and even respite that volunteers sometimes provide.

In the very last stages, some relatives and friends may feel awkward about visiting as they don't know how to communicate or what to do during the visit. This may make visits less frequent or drop off altogether which can be a great loss to the person with dementia and even his/her carers. Staff should work with and support carers e.g. giving guidance about how to communicate with the person with dementia and appreciate his/her smile, glance or the squeeze of his/her hand etc. (Simard, 2007).

Numerous methods have been used to mentally or physically stimulate people with dementia, to enhance communication and/or to provide relaxation e.g. multi-sensory stimulation, aromatherapy, music therapy, art therapy and validation therapy. Not all are appropriate for people with dementia at the end-of-life and not all non-pharmacological approaches are harmless. Further research into their effectiveness is needed.

Moreover, it should be borne in mind that people with dementia who dislike a particular approach may be unable to express their opinions. For example, some people may object to being touched or be disturbed by certain music which makes them feel sad, perhaps as a result of memories associated with it. If they cannot communicate how they feel, the measures which are used may actually be detrimental to their well-being. On the other hand, recorded music (of the person's own taste) and gentle touch/stroking of hands and face (if appreciated by the person with dementia) can be calming, reassuring and emotionally satisfying in end-of-life care for both the person with dementia and the carer/visitor.

People with dementia may experience a range of emotions such as sadness, anger and fear. Whilst an empathic response, along with reassurance or attempts to calm the person down may be helpful, for some people with dementia it may also

be beneficial to express these emotions e.g. through crying or shouting (Schmidl, 2006). Carers may find this disturbing and may need support in handling such signs of distress.

Finally, some people with dementia who have been suffering from depression continue to experience depression even though they have lost the ability to express themselves. For this reason, doctors may decide to continue treatment with antidepressants. But they need to be aware that dosage of all medication should be decreased in line with weight loss and severity of dementia.

Attempts should be made to ensure that the person with dementia appreciates any intervention used to enhance well-being.

Signs to the contrary should result in the intervention being stopped immediately.

Personal preferences must be respected.

Interventions should not be systematically applied to a captive audience.

Care should be taken to ensure that they are safe.

Practitioners of non-pharmacological interventions for stimulation, relaxation and communication should be suitably trained.

Visits from family and friends should be encouraged in residential care/ hospital settings. Additional visiting times or flexibility may be required.

Palliative care volunteers and volunteer organisations should be encouraged to visit people with dementia and trained in how to communicate with them.

The importance of human contact for the person with dementia should be emphasised.

People with dementia should be supported in the expression of their emotions.

Carers should be supported in dealing with emotional outbursts from people with dementia which they may find disturbing.

3.4.9 Communication

As dementia progresses the ability of the person with dementia to express his/her wishes and to understand others becomes increasingly difficult. Apart from the social aspect of communication and the need to express wishes related to the provision of care, people with dementia may have a need to communicate pain and suffering.

In the end stages, this can be extremely problematic. Some people with dementia in the final stage become very passive. Others communicate their feelings and needs but in very subtle ways which can all too easily go unnoticed unless carers

and professionals are familiar with their usual behaviour. The ability to understand non-verbal communication, the necessity to take time to communicate with the person with dementia and careful attention to specific techniques and conditions to enhance the possibility of communication are all important.

As pointed out by Allan (2001), communication is not an independent activity to be undertaken apart from other tasks but rather something which should be integrated into everyday practice. In fact, every contact with the person with dementia involves some form of communication. The tone of voice, facial expressions, eye contact and body language all form part of the communication.

Kitwood (1997) emphasised the importance of meaningful communication as a way to induce well-being and respect personhood.⁷

In several countries, live-in carers are legally or illegally employed from neighbouring countries (due to their low cost) and often they are not fluent in the language of the host country. Similarly, staff in carehomes and home help workers are not always fluent in the language of the country. This makes it even more difficult for people with dementia to understand and make themselves understood.

Attempts should be made to communicate with people with dementia and to inform them about relevant care issues even if this is difficult and time-consuming.

Whenever possible, this should be done in the person's own mother tongue.

Training in communication for dementia is vital for healthcare professionals and informal carers.

Measures should be taken to ensure effective communication between different healthcare professionals and between healthcare professionals and informal carers.

3.4.10 Spiritual care

Since the development of the hospice movement, the importance of spirituality has been recognised in end-of-life care. Holloway and Seicol describe spirituality as follows: "Spirituality is not what many think it is. Spirituality is to do with who we are and what life is about. It is not far away. It is very close to where we live. It has to do with our deepest longings, our sadness and joy, our loneliness and friendships, our fears and our times of trust, our beliefs and our disbeliefs. It has to do with the very essence of our being" (in Bell and Troxel, 2001).

Swinton (2001) describes it quite simply as being "that which gives meaning, purpose, hope and value to people's lives." As such, it could also be understood as covering the major existential themes described by Yalom (1980) i.e. death, freedom/responsibility, isolation/loneliness, and meaninglessness.

⁷ Please also see the previous sub-section on the social and built environment.

The “spirit” of any human being can be defined as their very essence, their unique identity, the one they were born with, which is still there right to the end, regardless of the ravages of dementia on their cognition, function, senses and emotions – all the things the world values. Caregivers and family members need help to look behind the effects of the illness to find value and cherish that essence – true spiritual care. Religious beliefs may or may not come into it (Pointon, 2008).

Spirituality is therefore a broader term than religion. Whilst many people express their spirituality through religious practice, others express it through their relationship with nature, music, the arts, family and friends or a set of philosophical beliefs (Sulmasy, 2002). In fact, there is a risk that nurses who equate spiritual needs with religious needs might overlook the spiritual needs of people who do not overtly practice a particular religion (Narayanasamy et al., 2004).

According to Sampson (2006), the spiritual needs of people with dementia are often ignored (only 40% were mentioned in case notes compared to 63% for people without dementia). For end-stage dementia, it cannot be assumed that just because the person has lost the ability to speak and fails to recognise people and places, he/she has no spiritual needs. Carers can be very helpful in informing professionals about the person’s beliefs. They might also arrange for prayers to be said, for priests to visit if the person with dementia was previously a churchgoer or for a rite of passage offering some kind of symbolic meaning to the person with dementia based on that person’s beliefs about life and death (not necessarily linked to religion). At the heart of all major religions is love, agape, compassion. But all human beings, whether religious or not, need to feel loved and cherished. When care is offered with love then a fundamental spiritual need is being met.

There are also people with dementia who approach death alone. They may have become distanced from their families or outlived them and lost contact with former friends. In such cases, professional carers, volunteers and church/charitable organisations may be the only ones in a position to provide spiritual support.

Professional carers are not always at ease with searching questions and statements about God, the meaning of life, death and suffering. These may be issues that they themselves avoid. Many do not profess a particular faith and may not have developed their own spirituality. They may be afraid of answering inappropriately, thereby causing further distress. Some do not recognise the importance of spirituality, seeing it as low on the list of priorities when compared with physical care. Representatives of churches, on the other hand, are likely to be at ease with spiritual issues but may find it difficult to communicate with people with advanced dementia. In all cases, the spirituality of the person with dementia may differ to that of carers and/or healthcare professional.

Finally, there are people who do not recognise or would not describe their own beliefs as spiritual (even if others would) and some people claim not to have any spiritual needs or beliefs.

Healthcare professionals should try to take a spiritual history of the person with dementia with the help of carers if necessary.

Spirituality should become an integral part of the care programme.

Whilst the spiritual, existential and religious needs of informal carers should also be addressed, care should be taken to ensure that catering for those needs is compatible with respecting those of the person with dementia.

In residential care settings, it should be clear who is responsible for the spiritual, existential and religious needs of residents.

As individual members of staff may be more or less sensitive to such issues, the ethos or spirit in the care establishment should be clear.

In some cultures there are certain symbols or practices which are associated with death. Nursing care staff should be attentive to people's beliefs and customs so as to avoid unwittingly causing distress.

In the case of people with dementia who have no relatives or friends, professionals carers should try to identify and respond to any spiritual, existential or religious needs they may have. It may be necessary to seek outside help e.g. from religious communities and representatives.

3.4.11 Cultural issues and minority groups

People with dementia from minority ethnic groups have been described as being at increased risk of experiencing disadvantage and more unsatisfactory service provision than people with dementia from the white majority population. Moreover, their knowledge about the existence of services and their expectations may be lower. There are also white minority ethnic groups (such as immigrant Polish and Ukrainians in parts of the United Kingdom) who may fail to benefit from culturally sensitive service provision as they are "invisible" (Innes, 2003).

There is a growing number of elderly people with dementia, whose national origins are not in their present country of residence, who revert to their native or childhood language as dementia progresses, producing complications in verbal communication, particularly for staff in care homes.

Respecting the different cultural backgrounds of people with dementia and carers is not just a question of religion and language but also of personal beliefs and values, dietary preferences, family dynamics and practices, the relationship with the wider community, social status and the impact of gender (Innes, 2003). It is also important to bear in mind that attitudes and behaviour of members of the majority group towards those from a minority group may occasionally be wrongly interpreted and lead to misunderstandings or even offence being taken.

In addition to ethnic minority groups, there are other minority groups such as gay and lesbian people, disabled people, people with learning difficulties, prisoners and people of no fixed abode who may have different priorities and life circumstances than those of the majority group. On the other hand, members of minority groups do not all share the same beliefs and practices. There are differences within and between all groups.

Palliative care providers should be aware of and respect the cultural beliefs and practices of people with dementia and their carers.

At the same time, stereotyping and making assumptions on the grounds that a person seems to belong to a particular minority group should be avoided.

Although professional carers should not be presumed insensitive or prejudiced, they may need support and training in dealing with their own feelings, as well as with negative comments which may be directed towards people from minority groups by other care staff, visitors or patients.

Standard service provision may need to be adapted to the needs of some groups of people.

Carers and people with dementia should not be required to disclose any information about their private lives to healthcare professionals.

Gay and lesbian partners who are carers should be treated as next of kin are treated – as partners in care and therefore involved in end-of-life decisions.

3.5 Guidelines on specific care issues

3.5.1 Pain management

Dementia itself is not painful but people with dementia may feel pain as a result of other conditions, including those caused by or linked to dementia and from other causes such as accidents resulting in bruises and broken bones. Yet according to McCarthy et al. (1997), people with dementia tend to receive less pain relief than those without dementia when they have the same illness.

3.5.1.1 Assessing pain

It is important to understand the cause of pain in order to treat it effectively but in the case of dementia, it can be difficult to recognise pain, to understand its cause and even to distinguish between pain and distress. People with dementia have difficulty communicating their pain and they may express it in a way that is not easily recognisable by others through behaviour. Even pointing to the source of pain may be difficult for people with dementia due to visuo-spatial deficits and an increasingly mask-like face or loss of movement in limbs in severe dementia can prevent presentation of the usual signs of pain or distress (Pointon, 2007).

Pain scales have been developed which are designed to detect pain in people who have difficulty communicating. Some are specifically for people with dementia. However, any pain scale is just one part of pain management and the same scale is not suitable for everyone with dementia. Skilled staff are therefore needed in order to select the most appropriate tool. Some (such as the DISDAT scale) are quite useful for distinguishing between pain and distress or discomfort. Whilst categorical scales may be useful for people with mild to moderate dementia, staff-rated scales might be more suitable for people with more advanced dementia (e.g. Doloplus).

Possible signs that a person with dementia is in pain include: facial expressions e.g. grimaces; body language e.g. restlessness, agitation, rocking, muscle tenseness, guarding a part of the body; an increased pulse rate or blood pressure; sweating; repetitive noises or inconsolable moaning. When assessing pain, simple terms should be used such as aching or hurting and parts of the body should be palpated whilst asking yes/no questions (provided that the person is not answering indiscriminately) (Australian Government, 2004). Alternatively, terms such as small, medium or large pain could be used. In addition, doctors should try to determine whether the pain is associated with movement, periodic or persisting, linked to eating or a procedure, worse when passing stool or urine, brought on by the application of light pressure and/or accompanied by skin changes in the area surrounding the pain (Regnard and Huntley, 2006).

As minor changes in the person with dementia may be a sign of pain, informal carers should be consulted and continuity of staff should be encouraged.

Carers should be asked about any previous pain complaints.

Behavioural and psychological symptoms of dementia, poor appetite and disturbed sleep patterns in a person with dementia should prompt a consideration of possible pain.

The possible existence of urinary tract infections, constipation, urinary retention and compression fractures should be considered.

Pain behaviours should always be investigated and not dismissed as “just part of dementia”.

Pain scales need to be further developed so as to be able to distinguish between chronic pain and acute pain and between pain and distress or discomfort.

3.5.1.2 Treating pain

Despite communication difficulties, it may be possible to narrow down the likely cause of pain to a few choices. This is important if the appropriate treatment is to be found. In some cases, treatment will involve the use of analgesics; in some cases it will involve other measures such as local cooling, antacids, laxatives and local creams etc. Further tests may be carried out in order to verify the exact cause of

pain and treat the condition causing the pain e.g. pressure sores, ulcers and various infections (Regnard and Huntley, 2006).

A procedure for treating pain in cancer patients was developed by the World Health Organisation (WHO). It has three main principles, namely that whenever possible analgesics should be given by the oral route, be given at a fixed time and be prescribed and administered according to the severity of pain and the response to the drug prescribed. Each step is associated with a different type of analgesic: step 1. non-opioid analgesics such as paracetamol; step 2. weak opioids; step 3. strong opioids. Additional drugs (“adjuvants”) may be used in combination with these drugs in order to calm fears and anxiety. It should be noted, however, that analgesics can also be given in the form of skin patches. This method of delivering pain relief could be useful for people with dementia, particularly if they have swallowing difficulties, and in care homes which do not have full-time medical staff.

Opiates sometimes have side effects such as constipation, nausea and vomiting, hallucinations, delirium and agitation, dry mouth, urinary retention, sleep disturbances and daytime drowsiness. Confusion is another possible side effect of opioids, but whereas opioids may increase confusion in some people with dementia, good pain control may lessen confusion in others. Codeine is known to sometimes worsen constipation and confusion. Carers may be concerned about the use of strong analgesics and the risk of shortening life though available evidence shows that adequate use of analgesics, including opioids, does not shorten life. Carers may also have fears about loss of awareness. Those from a Buddhist or Hindu background, for example, might be concerned about the person with dementia not being fully aware at the moment of death and some might consequently refuse analgesics.

Pain management should cover discomfort, distress and emotional pain as well as physical pain.

Attempts should be made to eradicate the cause of pain if possible rather than just treating it.

The WHO three-step ladder for treating pain in cancer patients should be adapted for the treatment of pain in end-stage dementia.

Doses of opioid analgesics and even of antibiotics should be adapted to body weight in patients with severe weight loss.

Weight, metabolism, individual response and the severity of dementia should be considered when treating pain, as well as a combination of signs such as severe chest infection, tachypnea, temperature, pulse and blood pressure.

Healthcare professionals should take the necessary time to explain to carers about the use of strong analgesics and the risk of shortening life, as well as about the loss of awareness.

Healthcare professionals should ensure that the correct dose is given in order to achieve the right balance between the alleviation of pain and the effects on awareness.

3.5.2 Feeding and swallowing problems

Most people lose interest in eating and drinking in the last days to weeks before death and this may be a signal from the body that death is approaching. In the final stage of dementia, loss of weight as well as of muscle and muscle strength is common. Certain drugs affect appetite as they cause nausea, mucosal irritation or delayed gastric emptying and can suppress appetite (Regnard and Huntley, 2006). Nevertheless, when people with dementia stop eating, there may be other reasons which need investigating such as pain, lack of trust (when being fed orally), feeling rushed or swallowing difficulties.

People with dementia may experience increasing difficulties swallowing (known as dysphagia) as dementia worsens resulting in a risk of aspiration (when food or liquid enters into the airway below the true vocal cords). This can increase the risk of aspiration pneumonia. This problem is sometimes managed through the use of a nasogastric tube (NG) or a percutaneous endoscopic gastrostomy (PEG) (often referred to as “tube feeding”) although studies have shown that PEG or NG feeding should be discouraged on clinical grounds for people with advanced dementia (Finucane et al. 1999, Li, 2002). These methods have not been found to be effective in preventing malnutrition, infections, pressure sores or aspiration pneumonia and it is sometimes necessary to apply restraint to prevent the person with dementia from pulling out a PEG tube (Summersall and Wight, 2006).

According to Volicer (2005), “Simple strategies involving hands-on care by well-trained staff – such as massage, oral hygiene, changes in diet and hand-feeding – can prevent infection and manage feeding problems without resort to tube feeding.” This kind of feeding also provides the person with dementia with the sensory benefits such as texture, smell and taste, as well as the emotional and relational benefits which result from interaction with a caring person.

Nevertheless, if assisted oral feeding is possible, certain precautions need to be taken to prevent the person with dementia from choking on food. Speech therapists or other healthcare professionals may be able to provide advice. A few basic guidelines (mainly from Morris and Murray, 1997) include the following:

- Try to avoid feeding the person when he/she is drowsy, agitated or lying down, as this could provoke choking.
- If possible, ensure that the person is seated in an upright position with the chin down and that he/she takes small sips of drink.
- Avoid vessels which force the head back too much (specially designed cups and mugs exist).

- Alternate food and drink to help clear the mouth.
- Encourage the person to try to swallow each mouthful of food twice (e.g. to swallow a second time even if the mouth is empty). If they have not swallowed, it can be useful to present an empty spoon.
- Encourage frequent swallows to counteract dribbling.
- Avoid mixtures of liquid and solid food (e.g. certain soups or cornflakes), stringy textures (e.g. cabbage, runner beans); floppy textures (e.g. lettuce, cucumber) and small, hard textures (e.g. peanuts and sweet corn).
- As people with swallowing problems will choke more easily on drink than on food, increasingly thicken drinks with prescribed thickeners.
- Beware of giving jelly or anything which turns to liquid in the mouth if the person is holding food pouched in the mouth due to swallowing difficulties.

People with dementia often have a diminished sense of taste as well as swallowing difficulties. Consequently, strong flavours are appreciated and insipid “invalid food” should be avoided. Savoury food can be pureed to a smooth, but not runny, texture using liquid and butter or cream cheese; sweet food and fruit can be combined with custard or other milk-based sauces. Cold drinks are more readily sensed and controlled in the mouth than warm ones.

Relatives need to understand that persistent weight loss in severe dementia is inevitable and part of the dementia process. Sometimes care home staff is wrongly and unfairly accused of neglect.

If the person with dementia refuses food or becomes unable to be fed orally and it has been decided to withhold or withdraw tube feeding, it is likely that death will result in about 14 days. This should not cause suffering provided that adequate measures are taken to ensure the person’s comfort e.g. keeping the person’s lips moist so as to avoid the sensation of thirst.

The withdrawal or withholding of food, taken either orally or by tube feeding, raises certain ethical questions which may be disturbing to those faced with making such decisions. Healthcare professionals should therefore reassure relatives that the person with dementia will feel neither hunger nor thirst provided that the lips are kept moist. Please see the Annex for a brief presentation of some of these issues.

 Tubes and PEGs for artificial hydration and feeding should not normally be indicated for people with end-stage dementia.

 For a persistent feeding problem, when everything has been tried and there is no response, they should not normally be used.

 If there is a sudden setback, they should be considered.

A PEG should only be used if it would improve the quality of life of the person with dementia.

Decisions linked to the use of tube feeding should be independent from economic, staffing, time and organisational issues.

Healthcare professionals should receive training in how to perform swallowing assessments and in adopting appropriate management strategies tailored to the individual. Management strategies include, for example, advice to nursing staff and carers on swallowing, modifying the diet, using food in purée form and thick liquids, correct positioning and feeding strategies.

Professional carers should take the necessary time for manual feeding.

Families should be informed about the pros and cons of tube feeding and consequences of withholding food and liquid.

It should be made clear that the person is dying as a result of dementia and not from starvation.

Carers should be given advice on how to feed the person with dementia.

Decisions about feeding should be taken well in advance.

3.5.3 Constipation, diarrhoea and incontinence

In advanced dementia, it is fairly common to eat less and have a reduced frequency of bowel movement. However, constipation may also be a problem. McCarthy et al. (1997) include constipation in their list of the six most common symptoms experienced by people with dementia (59%) in the last period of life.

Constipation may be caused by reduced intake of fibre or fluid and certain drugs such as analgesics. Moreover, dehydration, haemorrhoids and local tumours, which make passing stool painful, can also lead to fewer bowel movements. Certain medications that are used in the terminal stage of dementia can cause diarrhoea or constipation. Impaction may also result.

Hughes et al. (2007) point out that people with constipation have a tendency to lean to one side. This might be a useful sign to look out for in people who cannot communicate verbally. Concerning incontinence, practical measures include the use of incontinence pads and devices to collect urine (especially for men).

During the very last stage of life, doctors should consider discontinuing certain medication used in end-stage dementia if it is known to cause diarrhoea or constipation.

Permanent catheters for urine should not be used.

The excessive use of incontinence pads should be avoided.

Their use should be combined with good skin hygiene i.e. regular washing and the limited use of creams to prevent skin breakdown.

There should be sufficient staff to change pads regularly.

People with dementia should never be deprived of fluids in an attempt to control incontinence.

Attempts should be made to maintain continence for as long as possible.

Staff should be aware that standard procedures such as suppositories and enemas will not necessarily be effective if applied to people with severe dementia as the signals from the bowel and coordination of muscles to consciously bear down may well be affected.

Nursing staff should be aware that in certain cases a more direct/manual approach may be necessary, such as is used for paraplegics.

Daily laxatives can be counter-productive in people with dementia and create faecal leakage, with attendant skin problems. Keeping the stool soft is essential.

3.5.4 Pneumonia and infections

People with dementia in the terminal stage are particularly vulnerable to infections (e.g. pneumonia, bedsores and urinary tract infections), but as they are often unable to communicate, fever may be the only detectable symptom although sometimes there may be an infection but no fever. Long-lasting fevers have been associated with a higher rate of mortality. In some cases, there is no fever but the person may have become more confused.

Preventing people from becoming bed-ridden may help prevent pneumonia and bedsores. In some cases, the patient's brain will actually lose control of autonomic responses such as control of temperature as a result of the severe stage of dementia and a raised temperature may not necessarily be a sign of infection.

Pneumonia is considered a potentially life-threatening disease in end-stage dementia. It can be treated with antibiotics but this occasionally necessitates the use of restraint to prevent the person with dementia from removing the intravenous line (van der Steen et al. 2002). In the absence of knowledge about the wishes of the person with dementia, in the light of the already diminished life expectancy and on the basis of the condition of each person with dementia, some physicians and families consider that the burden outweighs the benefits and consequently withhold treatment (van der Steen et al., 2002). Nevertheless, in certain cases, antibiotics may still be a useful means of treatment for infections and to provide comfort.

The benefits and burdens of antibiotics should be carefully assessed for the treatment of pneumonia in end-stage dementia.

Preventive measures should be taken so as to reduce the likelihood of people with end-stage dementia getting infections.

Please also refer to the section on skin care.

3.5.5 Dehydration and mouth care

Dehydration involves the loss of normal body water. People who are terminally ill and dehydrated tend to have less urinary output which in some cases means fewer linen changes and hence less disturbance. Dehydration can also cause an electrolyte imbalance which can lead to muscle spasms and affect the level of consciousness but which can be treated (Alzheimer's Australia, 2006). A dry mouth (xerostomia) is another consequence of dehydration. Candida infection is possible and may in some cases extend to the upper gastrointestinal tract and through the gut but there are drugs for this condition (De Vries, 2003). Finally, according to Volicer (2005), maintaining oral hygiene serves as a protection against aspiration pneumonia. Once a patient can no longer talk or chew, then extra-care mouth hygiene with specialised cleansers is vital; carers and professional careworkers, especially in carehomes, may need extra training.

Evidence about the benefits of hydration is inconclusive. Whilst the process of dying may take a couple of days, people can survive with very little water for fairly long periods of time. Dehydration leads to the production of natural analgesics, and the breakdown of fat, carbohydrate and protein in the body produces water. These changes in the body bring about a feeling of calm and comfort or euphoria. People who are terminally ill often suffer from a dry mouth but evidence suggests that non-oral hydration does not prevent or treat this symptom (McCann et al., 1994). On the other hand, stopping hydration and food too soon does not necessarily hasten death and may result in prolonged discomfort due to problems associated with nutritional deficiency such as pressure sores (decubitus ulcers) (Regnard and Huntley, 2006).

Carers should continue to clean the person's teeth, giving him/her ice chips or frozen fruit juice to suck on and sips of liquid (e.g. tonic water or soda water), if this is possible without provoking a choking reaction. Don't attempt if there are swallowing difficulties! The person's lips should also be kept moisturised in order to avoid cracked sore lips and a little water could be sprayed into the person's mouth.

If the lips and inner lips are moistened, any sensation of thirst is satisfied. Carers can be shown how to wipe an ice lolly round the mouth. If this is made with a taste that the person with dementia likes, this also personalises the mouth comfort.

Eye drops should be applied if the person's eyes are dry.

3.5.6 Skin care

People's skin tends to become more fragile as they age and people with dementia risk developing pressure sores if they remain in bed or sit in a chair for long periods of time without moving. Sores can appear on any part of the body but tend to be on those parts which come into contact with the bed or chair. Although it is possible to treat them, they can be particularly painful and unpleasant for the person with

dementia who might be unable to recognise or communicate discomfort or associated pain. For this reason, it is important to try to prevent them from occurring.

At the first sign of loss of mobility, the patient should be provided with a pressure-relieving gel mattress and cushion before problems occur, not after. Reclining chairs are often more useful than armchairs for daytime use and prevent the patient from keeling over to one side. The chair should be suitable for each person. If there is severe weight loss, an alternating air mattress should be supplied. Home nursing also requires a hospital-type bed so that the angle of the upper body can be easily changed.

A healthy, balanced diet can help keep skin in good condition and therefore make it more resistant to sores. Regular exercise or movement improves the circulation and may help relieve a build up of pressure. For people who are bed-ridden, it might only be possible to regularly change their position. Otherwise, people could be encouraged to walk a little or rock from side to side in a chair.

An alcohol free moisturising cream could be used to hydrate the skin. However, this should be applied very gently and not massaged in because the skin could be very sensitive.

Carers should be informed about risk factors such as dehydration, under-nutrition, immobility, incontinence, sources of friction or pressure and anything which hampers circulation.

They should also be taught how to recognise damaged skin and look after pressure areas.

Damaged skin should not be rubbed or massaged when wet but rather patted dry.

In case of incontinence, pads should be used so as to avoid urine being in prolonged contact with the skin (as it can make the skin spongy and less resistant to sores).

Pressure relieving devices should be introduced as soon as the person with dementia loses mobility. Such devices may also reduce pain in the case of existing pressure sores (decubitus ulcers) and be helpful in cases where the person is uncomfortable in a chair.

In case of serious damage to the skin, expert nursing should be provided.

In the very last moments of life, when the prevention and treatment of bed sores is no longer a priority, resting the person in his/her preferred position may be the best option.

3.5.7 Body temperature

Older people are less able to respond, through homeostasis, to changes in body temperature. In addition, many people in the advanced stage of dementia lose weight which means that heat from the body is lost more quickly. They may also lose the shivering reflex, which is the body's way to generate heat. Hyperthermia is a risk as they may fail to recognise and respond to changes in ambient temperature. If they are also dehydrated, this could be very dangerous.

Carers should be informed about the risk of hyperthermia.

Extra vigilance is required.

Please also refer to the section on pneumonia and infections.

3.5.8 Sedation

Anti-psychotic drugs are often used to treat people with dementia who are experiencing anguish, agitation, delirium, confusion and hallucinations. The drugs sedate the person and are sometimes inappropriately used to manage untreated pain or because carers find it almost unbearable to witness the suffering of the person with dementia. The over-treatment of pain can also result in sedation so it is important to get the balance right. However, recent research suggests that the long-term use of anti-psychotic drugs has no benefit to most people with dementia and that it leads to a marked deterioration in their verbal fluency (Monschein, 2008). Moreover, preliminary analysis suggests that anti-psychotic drugs may increase the death rate of people with dementia.

It is particularly important to avoid the unnecessary and inappropriate use of sedation in the final stage of life as people with dementia often have a period of lucidity immediately prior to death and this can have a positive and profound impact on the bereavement process of relatives and care staff (De Vries, 2003).

Playing familiar music can calm agitation or distress. People with dementia need above all to feel safe and cherished, especially in the end stages, and gentle stroking of hands, feet or face, quiet talking and eye-contact from a smiling, reassuring face can be more effective than the medicine bottle. Also burning certain aromatic oils – such as lavender - can have a relaxing effect. Just someone quietly being there may in itself provide the necessary reassurance and it is especially important in carehomes that people with dementia are not left alone in their rooms for long periods of time. An individual approach is important.

Anti-psychotic drugs should be used with caution bearing in mind the points raised above and taking into consideration the person's weight.

Other methods should be considered to calm the person and reduce agitation or distress.

In case of agitation, the possible existence of pain should be investigated.

Unnecessary sedation should be avoided as it might rule out the possibility of a period of lucidity just before death and might not be in accordance with the wishes of the person with dementia.

3.5.9 Restraint and falls

Due to gait apraxia, unsteadiness and limited mobility, elderly people with dementia are more prone to falls than elderly people in the general population (Cotter, 2005). Even those who are bed-ridden could fall from the bed or a chair.

Often when a person with dementia is displaying “challenging behaviour”, the behaviour has been triggered by something in the environment or is the result of pain, discomfort, lack of understanding or frustration. Mechanical restraint is sometimes used in cases where there is a risk that the person with dementia might pull out tubes or fall out of bed. However, the use of restraint can be stressful, provoke negative emotions such as anger, fear, resistance, humiliation and demoralisation and even exacerbate a situation which is already difficult. It can actually lead to accidents and is not allowed in some countries.

For this reason, before sedation or restraint is used, an assessment of the person’s behaviour and of the situation and possible contributing factors should be made. Any other possible interventions should be considered first.

The use of restraint can lead to falls as people may struggle to free themselves from restrictive measures and/or are drowsy or confused as a result of sedation or other medication. People may even fall as a result of struggling over barriers (e.g. bed rails) or as a result of unsteadiness or fatigue following the effort to free themselves from a restrictive measure (Cotter, 2005).

Yet according to Wang and Moyle (2005), there is no scientific evidence to prove that physical restraint protects people with dementia in residential care from injuries. An earlier study found that the risk of fall associated with the use of restraint was not dependent on the effect of psychoactive drugs (Capezti et al., 1996).

The use of restraint can lead to acute functional decline, incontinence, decubitus ulcers and regressive behaviour particularly in older people with dementia in a relatively short period of time. It can even lead to death, often as a result of asphyxiation, strangulation or cardiac arrest (e.g. as the person becomes trapped between the headrest, mattress and bedrail) (Cotter, 2005).

Certain forms of care, such as the use of fixed catheters, might also be considered as restraint if the person objects to them and if they are used more for the benefit of healthcare professionals.

An individualised assessment should be made and any other possible intervention considered before resorting to the use of restraint.

Healthcare professionals should adopt a restraint-free philosophy and develop suitable alternative interventions.

Carers should be informed about the risks linked to the use of restraint.

Physical and mechanical restraint should only be used in exceptional circumstances.

If used, this should be recorded in the person's medical file and the person with dementia should not be left alone whilst under restraint.

3.5.10 Difficulty breathing and “the death rattle”

Breathlessness is quite common in severe dementia but carers can be taught simple measures to ease the sensation. This includes sitting the person upright, increasing the air flow around the person's face by opening a window or using a fan, helping the person relax the shoulders so as to avoid “hunching” and facilitate breathing and providing reassurance (Regnard and Huntley, 2006). Comorbidity can complicate and cause breathlessness.

When the person with dementia is close to death, he/she may experience more severe breathing difficulties. This can be frightening not only to the person with dementia but also to carers. It might involve gasping for breath and a panicky feeling or what is sometimes referred to as the “death rattle” whereby secretions from the lungs and throat obstruct the central airways. Air passes over the secretions and produces noisy ventilation with each breath. It may help to explain to carers what is happening and that the person is not choking, perhaps comparing the noise to snoring (Bickel and Arnold, 2004).

Other measures include using oxygen (provided that the person with dementia does not pull out the nasal prongs or pull off the mask), suctioning the upper airways (but this may be uncomfortable for the person with dementia) and giving medication to reduce excess secretions (Alzheimer's Australia, 2006). The medication may dry up all secretions and cause discomfort e.g. of the eyes. Morphine can also have this effect which is why it is important to find the right balance. Oxygen also helps to relieve the severity or length of tonic-clonic seizures (formerly known as epileptic fits), myoclonic jerking and dry out breathing in the last stages (Pointon, 2007). Medication may be needed if the breathlessness is accompanied by intense fear.

Carers should be taught how to manage mild breathlessness.

They should also be informed about what is happening and be given reassurance.

Professional carers should consider additional measures to prevent or deal with more severe breathing difficulties.

If the breathlessness is very severe and persistent, a palliative care specialist should be consulted.

3.5.11 The moments preceding and following death

3.5.11.1 *The process of dying and after*

As Evers and Sutton (2007) point out, “It is very difficult to assess when a person stops living with dementia and starts dying from it.” The uncertainty of not knowing can be especially difficult for carers to deal with and medical staff need to know when death is near in order to provide the most appropriate treatment and care.

In the last 48 hours of life, the following symptoms are most common in people with dementia: pain, dyspnoea (shortness of breath), respiratory congestion, delirium, dysphagia (difficulty swallowing), fever and muscle twitching (Australian Government, 2004). Deterioration tends to occur more rapidly, the person becomes increasingly drowsy or comatose and takes very little food, fluid or oral medication (Regnard and Huntley, 2006). When death is imminent, the skin is cool to touch and there are changes in pulse rate and breathing pattern (de Vries, 2003). The ability to recognise these signs is extremely important as it has implications for certain medical and care decisions that need to be taken in the moments preceding death and in order to allow people with dementia, carers and staff to prepare themselves emotionally for this moment. It also gives carers the time to get to the hospital or care centre before it is too late and for close family members and friends to gather. Nevertheless, some people with dementia have very few symptoms, perhaps just starting to get cold or a slight change of colour.

Privacy and the presence of a caring person, perhaps but not necessarily involving gentle touch such as holding the person’s hand, is something that may be beneficial to the dying person.

Regnard and Huntley (2006) describe the last hours or days of life as being more of a gentle winding down rather than any sudden presence of death. The signs and symptoms, which are typical of this winding-down process, include fixed and dilated pupils, the sound of fluids within the body and stopping breathing. This may be disturbing to carers. In addition to the clinical signs that a person with dementia is approaching death, there is anecdotal evidence that relatives or those close to the dying person simply know when the end is very near and that this is based on their daily contact with the person with dementia.

Some religions have certain rites and rituals which should be carried out at the moment of death or shortly before. In Islam and Judaism, for example, it is important that the dying person is not left alone as he/she dies. Catholics may wish to ask for a priest to administer the Sacrament of the Sick (known as “last rites”). There may also be a highly ritualised procedure for the time following death involving rites to honour the deceased person and help those left behind (e.g. in traditional Judaism). The proximity of relatives extends beyond the moment of death until the person is buried and arrangements may have to be made to ensure that someone watches over the deceased person (Bauer-Wu, 2007).

Doctors should estimate the predicted time of death in collaboration with those closest to the person with dementia.

Carers should be informed in advance about the kind of symptoms they might observe.

Carers should be provided with further reassurance at the time if needed.

Privacy should be provided. This might involve moving the person with dementia from a general ward into a private space.

Measures should be taken to ensure that carers have the opportunity to be present during the last moments of life of the person with dementia.

In order to ensure that the dignity of the person with dementia is respected, certain care issues should be considered and planned in advance (e.g. how to deal with possible incontinence, how the person is dressed, who is present, whether the person is in bed or seated etc.)

The beliefs and traditions of individuals should be respected before, during and after the death of the person with dementia.

3.5.11.2 *Grieving and mourning*

For many carers, the grieving process starts long before the death of the person with dementia. Over the course of the disease, they may have experienced numerous losses (e.g. loss of things they planned to do together, loss of the ability to share a conversation and discuss problems, loss of aspects of the person's character they used to appreciate and loss of the roles the person used to fulfil such as partner, lover, parent, cook, gardener etc.). Some feel that the person they once knew died a long time ago and go into premature mourning (Blanchard, 2006).

The actual death of a person with end-stage or severe dementia may provoke a range of emotions. Whilst sorrow and grief are common reactions, some people simply feel numb or devoid of any emotion. Others experience a certain degree of relief. They may see death as a release from a long period of suffering during which the quality of life of the person with dementia seemed greatly reduced. Some may also feel relieved that the period of intensive caring, which can be physically and emotionally exhausting, is over. Such feelings may help in the period immediately following death but can, as time passes, lead to feelings of guilt over the apparent absence of sorrow.

People who witness a badly managed death, in which the person with dementia seemed to be in pain and having difficulties breathing, also tend to experience more grief, guilt and regret during the bereavement process (Australian Government, 2004). It is also in the period following death that carers might question care decisions which they took earlier and even wonder if they are in some way responsible for the person's death.

The death of the person with dementia can also leave a void in people's lives. Some carers provide round-the-clock care, particularly in the last stage. Often, it is as if their own lives have been put on hold. They stop doing the things they once enjoyed and gradually lose contact with their friends and acquaintances.

For some people, it may be months before the loss really hits them. At that time, outside support may be less forthcoming and it might be difficult for outsiders to understand what they are going through.

Professional carers are generally expected to provide support to carers during the dying process yet the dying person may awaken fears about death in them or they may have become close to him/her during the course of caring. Some may have learnt to maintain a distance from patients but this could be interpreted as transforming the person with dementia into an "object" of care as opposed to a person (Blanchard, 2006). Clearly, some do occasionally experience grief over the death of a patient. At such times, they may find themselves in the difficult position of trying to provide support to carers whilst at the same time dealing with their own grief.

Carers, relatives and close friends should be provided with support following the death of the person with dementia.

Such support should not be limited to the period following death but should be available at any time that it is needed.

Appropriate ways to deal with delayed grief and mourning should be investigated.

Grief reactions of professional carers should be recognised as legitimate and appropriate support provided if necessary.

3.6 Annex: A brief consideration of a few ethical issues

In this annex, a few issues are briefly presented as they have some relevance to the end-of-life care of people with dementia. We decided to base our guidelines solely on the practical issues linked to good end-of-life dementia care and not necessarily to state our position on ethical issues per se at this stage. Nevertheless, as the practical and ethical issues are inextricably bound, this section is intended to briefly present some of the issues and debates which may have influenced our guidelines on good end-of-life care for people with dementia.

Issues covered include:

- Personhood
- Autonomy and capacity
- Beneficence and non-maleficence
- Justice/equity

- Cultural issues linked to principles of bioethics
- Withholding and withdrawing treatment
- Futile or over-zealous treatment
- Dilemma between saving life and respecting patient's wishes
- Discrepancy between current and former wishes
- Research
- Euthanasia

3.6.1 Personhood

The nature of identity and the value of the subjective experience and lives of people with advanced dementia have been much debated. Such issues are of relevance to ethical debates about personhood. Personhood is sometimes considered as being dependent on the possession of a particular facet of human existence such as self-consciousness, rationality or memory. In such cases, the personhood of people who are found to be lacking it is questioned or denied. Others argue that as with the concept of inherent dignity, personhood should be understood as something which resides within all individuals and not as something which is granted to them or withheld by other people (Dylan, 2007).

For example, there is sometimes a tendency to erroneously associate the loss of cognitive abilities with the loss of the quality of being human (Blanchard, 2006). Some theorists have called into question the personhood of people with advanced dementia (Kuhse, 1999 and Buchanan, 1988) but others (e.g. Killick, Barnett, Ignatieff and Goldsmith) would suggest that people with severe dementia have awareness and a voice which can be heard if one listens to it (Cox, 2003).

Nevertheless, even relatives and close friends sometimes have difficulty recognising the personhood of someone with end-stage dementia as his/her current state is so different to their memory of what it used to be.

Alzheimer Europe objects to “any attempt to classify people with dementia at any stage of the disease as anything other than full human beings entitled to the same amount of consideration and respect as any other group of people” (Alzheimer Europe, 2006).

3.6.2 Autonomy and capacity

The term autonomy is used to describe people's ability to express their will and lead their lives in accordance with their own values and convictions. Autonomy is a central principle in health care. The medical profession in Western Europe is gradually moving away from a paternalistic approach towards a more individualistic, client-centred approach whereby patients are expected to play a more active role in

decision-making linked to their own health and well-being (Mallia, 2003). Such an approach requires that patients take responsibility for making their own decisions provided that they have the necessary capacity to do so.

In all Member States of the European Union, adults are presumed to have legal capacity unless proven otherwise (Alzheimer Europe, 2006). Protective measures are arranged by the State for people who are assessed as lacking capacity. However, it should be borne in mind that people can have different levels of capacity in different situations and for different types of decision. Deciding whether to stay in bed or sit by the window does not require the same degree of decision-making capacity as deciding whether or not to have tube feeding or antibiotic treatment. Limited capacity is also possible in the sense that a person may need assistance to make a decision but still be able to contribute towards the decision-making process. Assessment of capacity should therefore be limited to a particular situation or decision that needs to be made and not carried out on a once and for all basis (Alzheimer Europe, 2006).

People with end-stage dementia are likely to have limited capacity to make complicated treatment decisions and/or have difficulty expressing their wishes. However, some people with dementia who are dying are not in the end-stage and may have sufficient capacity for certain decisions.

Attempts to determine the person's wishes may be time-consuming but good end-of-life care involves professional carers taking the necessary time and consulting advance directives, statements of values, healthcare proxies and carers. If the person with dementia has expressed a wish to be cared for at home, fulfilment of this wish may be dependent on the ability and wishes of relatives and close friends, as well as the provision of support from the State (particularly if the person lives alone). As such, the right to exercise self-determination is not absolute but must be negotiated and exercised within a particular context.

3.6.3 Beneficence and non-maleficence

The term beneficence has been used in literature on biomedical ethics since about 1975 to refer to the principle of balancing the risk of harm to a patient with the possible benefits which might occur as a result of a particular treatment or course of action (Stanford University, 2008). As such, it is not limited to non-maleficence which simply involves not causing harm. This is important as sometimes a certain degree of pain, discomfort or risk is necessary in order to prevent a more serious (and perhaps more painful) condition.

When deciding on end-of-life treatment for people with dementia, the risk of developing more serious conditions is perhaps less relevant due to the extremely limited life expectancy of patients. The risks and potential burden involved in any particular treatment are also subject to individual as well as medical interpretation and may be linked in some cases to judgements about the value and quality of life. In

the case of palliative care of people with dementia, there is a danger that blanket judgments will be made about the value or quality of life of people with advanced stages of dementia, that insufficient information will be sought about patients' wishes and that opinions about the value or quality of life may be projections of decision makers' own feelings about such issues.

3.6.4 Justice/equity

The principle of "justice/equity" could be described as the moral obligation to act on the basis of fair adjudication between competing claims. As such, it is linked to fairness, entitlement and equality. In health care ethics, this can be subdivided into three categories: fair distribution of scarce resources (distributive justice), respect for people's rights (rights-based justice) and respect for morally acceptable laws (legal justice) (Gillon, 1994). Palliative care services are not particularly well-developed throughout Europe and access to existing services is often restricted to people with cancer. Yet people who are dying with/from dementia are every much as entitled to palliative care as people with cancer.

The right to be treated equally, and in some cases equal access to treatment, can be found in many constitutions, but in practice, a number of different factors may influence actual access to treatment e.g. age, place of residence, social status, ethnic background, culture, sexual preferences, disability, legal capacity, hospital budgets, insurance cover and prognosis. For example, the Swiss Academy of Medical Sciences recently reported that doctors and other medical staff are increasingly refusing to administer potentially useful treatments for economic reasons (SAMS, 2008).

In the healthcare setting, certain people or groups of people may find that they are not being treated with equal respect e.g. with indifference, unfriendliness, lack of concern or rudeness.

3.6.5 Cultural issues linked to principles of bioethics

Autonomy, beneficence, maleficence and justice were described by Beauchamp and Childress (1994) and are part of one of the most widely used frameworks for considering bioethical principles. It could be argued that this is a Western approach to bioethics but according to Aksoy and Tenik (2002), "these principles are universal and applicable to any culture and society; these principles have always existed in different moral traditions in different ways." In particular, the bioethical principles of the three main monotheistic religions (namely Judaism, Christianity and Islam) are not radically different although beliefs may differ between different local communities practising the same religion.

The main Jewish documents of reference are the Bible, the Talmud and the Responsa literature. In addition, there are established norms for laws and behaviour known as the Halacha ("the way"). In traditional Judaism, interpersonal relationships are important and people are expected to act as "responsible stewards" in preserving

their bodies which belong to God. The doctor-patient relationship is not considered as a voluntary-contractual relationship but rather one based on the patient's divine obligation to seek healing and prevent illness. A certain degree of patient-autonomy is nevertheless accepted within the relationship (Steinberg, 2008). There is an obligation to do whatever is necessary to heal oneself and it is clear that life should not be taken before its time. The question which therefore arises is at what point the process of dying can be considered to have begun (Goldsand et al., 2001).

There are several branches of Christianity one of which is the Roman Catholic Church. Catholic bioethical reasoning is based on traditions expressed in the scriptures, the writings of the Doctors of the Church, papal encyclical documents and reflections by contemporary catholic theologians (Markwell and Brown, 2001). Catholics have a fundamental belief in the sanctity of life, the possibility of an afterlife and that each person is made up of a body and a soul. Consequently, as long as there is a living body, there is also a soul and hence a person. Whilst the four bioethical principles are compatible with catholic thinking, other concepts such as hope, love and faith may also influence end-of-life decision making. As far back as the 16th century a distinction was made between ordinary measures to preserve life and extraordinary measures. Failure to use ordinary measures was regarded as being morally equivalent to suicide which is rejected by the Catholic Church. However, determining what is ordinary and extraordinary in each situation is primarily considered as being the right of the patient and his/her family. Consideration of this issue can be influenced by financial issues and burden to others.

Islamic bioethics is based on the Shar'ia (Islamic law) which is itself based on the Qur'an and the Sunna. It stresses duties, obligations and the prevention of illness, but when this fails, Islamic bioethics provides guidance both to doctors and patients (Daar and Khitamy, 2001). Patients must not only be treated with respect and compassion but their physical, mental and spiritual well-being must also be taken into account. Nevertheless, when treatment becomes futile, it ceases to be mandatory (Shahid, 1995). According to Kao (2002), a greater emphasis is placed on beneficence than on autonomy especially at the time of death.

The Buddhist and Hindu belief in reincarnation may, according to Campbell (in Kenel-Shank, 2005), result in some people wanting to be conscious at the moment of death and therefore refusing analgesics. This seems to imply a greater emphasis on respect for autonomy than on beneficence or non-maleficence. On the other hand, Kishore (2003) explains that end-of-life decisions for Hindus must be understood within the Hinduistic concepts of Dharma, Karma and non-attachment, continuity, liberation, beneficence and compassion. He further states that when Hindus make decisions about end-of-life, they are considering life as a human body or human person but also as the "eternal and perpetual cosmic phenomenon passing from one body to another".

Clearly, healthcare professionals, people with dementia and carers from ethnic minority and/or religious groups living in Europe may have priorities and approaches to end-of-life decision making which are different to those of the majority group. On the other hand, people who practice certain religions do not necessarily hold the official beliefs of that religion.

3.6.6 Withholding and withdrawing treatment

Tube feeding is considered a medical act and as such is not part of normal care. Withholding or withdrawing tube feeding does not constitute wilful starvation, euthanasia or assisted suicide. On the contrary, it is a treatment decision. Ideally, issues surrounding the use of tube feeding should be discussed well in advance and recorded in an advance directive.

In some countries, relatives and close friends may be consulted when decisions about tube feeding have to be made if there is no record of the wishes of the person with dementia and he/she lacks the capacity to make a decision. This can be a difficult decision to make. Giving food to a person is not just a practical matter linked to the maintenance of his/her physical body but also fulfils the symbolic role of caring for a person (Dunlop, 2006).

Dementia is a terminal illness and at the end stage, "not eating" may well be a marker of the dying process and not the cause. Ethically speaking, there is no difference between withholding or withdrawing a treatment but the decision to withdraw a treatment may be emotionally more difficult. Relatives may fear that in deciding to do so, they are responsible for causing the person's death.

Moreover, doctors have a duty to preserve life but not to inappropriately prolong dying. Their own beliefs about tube feeding and/or the appropriateness of tube feeding for a particular person in a particular situation may differ from those previously expressed by the person with dementia or currently expressed by relatives. Alzheimer Europe does not believe that doctors should ever be obliged or pressurised to act in a way that runs counter to their professional or personal beliefs and values.

Finally, there is a risk that cost might influence tube feeding decisions if the cost and reimbursement of tube feeding and assisted oral feeding differ. In America, for example, many nursing homes receive a higher reimbursement from Medicaid for tube feeding people with dementia than for feeding them by hand (Volicer, 2005).

3.6.7 Futile or over-zealous treatment

Medical treatment can be described as futile if it is unlikely to be of benefit to a particular patient in a particular situation. Futile treatment is sometimes relentlessly pursued even though it does not correspond with the patient's own goals and/or the benefits do not outweigh the burdens of the treatment. The philosophy and

practice of palliative care is clearly opposed to futile and burdensome treatment but in general hospital settings, there is a risk that medical staff do not recognise dementia as a terminal illness or the signs of end-stage dementia with the result that people with advanced dementia may be subjected to burdensome treatment.

There is also a risk that decisions which should be based on the probability of possible benefits and burdens are actually influenced by economic factors, e.g. a treatment is withheld so that the dying phase is not “unnecessarily” extended (and hence a bed is vacated), a particular treatment or intervention is withheld as it is too expensive or a particular treatment is given in order to reduce the burden on care staff.

3.6.8 Doctors’ dilemma to preserve life but also respect patients’ wishes

With regard to end-of-life decision making, doctors are in a potentially difficult moral position as their deontological codes and training emphasise the duty to save or preserve life. This may be in conflict with the duty to “do no harm”, and also with the best interest of the patient. The Hippocratic Oath, which forms the basis of pledges which some doctors still take upon entering practice, does not actually state “First, do not harm” (as is sometimes believed). It does however state that treatment should be given that is in the best interests of the patient and that lethal doses of medicine should not be administered or prescribed. Translations of the oath vary but one modern day version of the oath includes the following paragraph:

“I will follow that method of treatment which according to my ability and judgment, I consider for the benefit of my patient and abstain from whatever is harmful or mischievous. I will neither prescribe nor administer a lethal dose of medicine to any patient even if asked nor counsel any such thing nor perform act or omission with direct intent deliberately to end a human life. I will maintain the utmost respect for every human life from fertilization to natural death and reject abortion that deliberately takes a unique human life” (Angelo et al. 1995).

In end-of-life care, the boundaries between doing what is in the best interests of the patient and respecting his/her autonomy are often blurred. Moreover, the principle of double-effect (mentioned below) involves administering high doses of analgesics in the full knowledge that this may bring about the patient’s death. Withholding or withdrawing treatment may be in the best interests of the patient and in accordance with his/her wishes but nevertheless directly linked to the ending of that person’s life. In countries where euthanasia or doctor-assisted suicide is permitted, doctors may find themselves asked to do something that they are opposed to. Whilst they are free to refer patients to other doctors who are not opposed to such practices, the good doctor-patient relationship that they have built up cannot be transferred and patients may therefore find themselves amongst unfamiliar doctors during their last moments.

3.6.9 Discrepancy between current and former wishes

Clear and unambiguous wishes expressed in an advance directive may help doctors to decide on a course of treatment or care. However, a problem arises when alongside a valid advance directive, a patient has current wishes (regarding proposed treatment for which he/she does not have decision-making capacity) which may be more or less clearly expressed, more or less consistent and more or less in agreement with the view expressed in the advance directive. There is also the difficulty that sometimes when the advance statement is made the decisions are made on gut feelings rather than being in possession of the full facts. It requires very sensitive support to tease out the right decisions for the individual person. This can create a dilemma for doctors who are then put in the position of having to choose between formerly and currently expressed wishes. This issue is also related to the ethical discussions about personal identity and the extent to which the person who wrote the advance directive remains the same person over time and as a result of cognitive decline.⁸

In its position paper on advance directives, Alzheimer Europe stated its opinion that:

“(…) if advance directives are to be taken seriously, the wishes contained in such documents should generally be respected. There are, however, two exceptions:

- Current competently expressed wishes cannot be overridden, and
- Nobody should be subjected to medical treatment or suffer from a lack of medical treatment on the basis of a prior decision when it is obvious that they are currently displaying clear and unambiguous signs of wishes to the contrary.

In such cases, staff should be able to act humanely in accordance with current professional standards and taking into consideration the context and the doctor-patient relationship and on the basis of good communication between all concerned, including the person with dementia. The advance directive should be regarded as part of this communication.”

3.6.10 Research

Most people with end-stage dementia would be unable to give informed consent to participation in research (due to reduced capacity and communication difficulties). Proxy decision makers might, in certain cases, be able to consent on their behalf but their views may differ from those of the person with dementia. Also, as they are expected to act in the best interests of the person with dementia, this would not normally include consenting to research involving any kind of burden unless some kind of benefit was likely for the person with dementia. Yet this might be what the person with dementia would have wanted.

⁸ For more details, please refer to: Alzheimer Europe (2006), Alzheimer Europe Report – The use of advance directives by people with dementia, Alzheimer Europe

Consent to future research in an advance directive would be helpful but could also be more problematic than consenting to treatment in advance. As pointed out by Berghmans (1998), it is difficult to give consent for a future experiment which has not yet been devised and which, by the nature of research, is likely to be innovative.

Whether or not people who are unable to consent should be involved in research is an ethical issue which was addressed in the Council of Europe's Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (1997). The convention differentiates between therapeutic and non-therapeutic research, stating that the latter should not normally be carried out on people who are unable to consent. There are two exceptions to this rule, which make non-therapeutic research on subjects who are unable to consent possible, namely:

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

The International Ethical Guidelines for Biomedical Research of 2002 allow for levels of risk which are slightly higher than those linked to routine medical or psychological examinations if there is an overriding scientific or medical rationale for the study and provided that an ethical review committee has approved the study.

With regard to therapeutic research, it is clear that research based on care issues, quality of life, identification and treatment of pain and certain other topics might benefit people dying with/from dementia. Nevertheless, inflicting even minimal burden would be contrary to some of the aims of palliative care such as maximizing comfort, alleviating pain and maximizing quality of life.

3.6.11 Euthanasia and assisted suicide

Active euthanasia and assisted suicide, including doctor-assisted suicide, all involve in some way helping a person to end their life. Active euthanasia involves actively bringing about the death of the person e.g. by means of a lethal injection. Usually, the person has a terminal condition, is experiencing intense suffering and wishes to end his/her life. In Belgium and the Netherlands, this form of euthanasia has been legalised, subject to certain conditions being fulfilled, and this may soon be the case in Luxembourg. In Switzerland, active euthanasia is illegal but doctor-assisted suicide is tolerated (provided that the correct procedure is followed and that

it is officially declared). With the latter, the doctor provides the necessary means for bringing about death but it is the person who wishes to die who carries out the act.

However, Alzheimer Europe recommends palliative care for people with end-stage dementia which is an approach which does not attempt to prolong life or hasten death, the emphasis being on ensuring quality of life and a “good death”. Consequently, the debate about active euthanasia and doctor-assisted suicide is not relevant to this document.

On the other hand, within palliative care, life-sustaining treatment is sometimes withdrawn or withheld e.g. when it is felt that it would not result in sufficient benefit to the patient or if it would be burdensome⁹. This is sometimes referred to as passive euthanasia even though many doctors argue that there comes a time in the course of treatment of a patient when treatment no longer has any effect and when the burden outweighs the benefit. This could be the case for artificial nutrition and hydration in the last moments of life.

The association between withdrawal and withholding of nutrition, hydration or other forms of treatment and the use of the term “passive euthanasia” may be disturbing to carers faced with such decisions. Yet according to Materstvedt et al. (2003) the withholding or withdrawing of futile treatment should not be considered as an act of euthanasia. In their opinion, euthanasia is active by definition and consequently, “passive euthanasia” is a contradiction in terms.

“Double effect” refers to the administration of large doses of opioids (to the extent that this is clinically necessary) to alleviate pain in the knowledge that such doses could possibly hasten the death of a patient. This is not considered as euthanasia as the intention is to relieve suffering and not to hasten the death of the patient. As mentioned earlier, the problem in the case of dementia is that people with advanced dementia are often given insufficient amounts of opioids rather than too many. Moreover, in specialist palliative care, these drugs are very carefully titrated to the individual in order to ease symptoms and avoid toxicity. Consequently, they do not shorten life and there is no double effect.

⁹ In some countries, such as the UK, nutrition and hydration count as treatment.



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Alzheimer Europe's position and recommendations on end-of-life care cover the very last stage of life of people with dementia. It starts with an executive summary of the main recommendations contained in the report, divided into four sections: people with dementia, carers, healthcare professionals and policy makers/the State. This is followed by very detailed guidelines of numerous aspects of end-of-life care, not just the physical care but a wide range of issues linked to end-of-life care such as dignity, spirituality, communication, and interaction between carers and healthcare professionals to name but a few. It is a non-judgemental and pragmatic approach to the good end-of-life care of people with dementia and support to carers and will hopefully be of interest to carers, healthcare professionals, researchers and policy makers.

