Alzheimer Europe – 2009 Operating grant agreement
Agreement Number 2009 32 01
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1 Introduction

Alzheimer Europe identified six key activities and projects for its 2010 work programme. These activities of the organisation are focused on the promotion of mental health and the fight against stigma identified in point 3.3.2.6. of the Commission Work Plan. The organisation also focused in the priority on mental health of older people in the European Pact for Mental health and Well-being and its priorities of promoting the active inclusion of people with mental health problems in society and taking measures to support carers.

AE planned on doing so by establishing a network to support carers in dealing with ethical issues arising in the care of people with dementia, identifying way of promoting the active participation of people with dementia and carrying out an inventory of laws on guardianship and proxy-decision making decision in the Member States of the European Union.

The six key activities and projects indentified by the organisation were:

1. European Dementia Ethics Network
2. Legal Rights Project
3. Involving people with dementia
4. European Dementia Observatory
5. 20th Alzheimer Europe Conference in Luxembourg
6. Organisational issues
2 European Dementia Ethics Network

2.1 Aims

The European Dementia Ethics Network had three key aims:

- Collecting ethical positions and recommendations by different professional and/or medical organisations and thus becoming a reference on ethical issues in the care and treatment of people with dementia,
- Providing in-depth coverage of special ethical dilemmas and developing, where possible, consensual positions on such ethical issues,
- Collecting requests of individual carers and health care professionals faced with ethical dilemmas and providing guidance when possible.

In 2010, the focus of the network was on ethics of assistive technologies.

2.2 Achievements and results

The launch phase of the European Dementia Ethics Network was successfully completed in 2009 with the support of the German Health Ministry and the organisation had created a European Dementia Ethics Steering Committee and developed a section of its website dedicated to dementia ethics. The implementation phase of the network was successfully started in 2010.

In 2010, the Steering Committee was comprised of the following experts:

- François Blanchard (France)
- Alain Franco (France)
- Jean Georges (Alzheimer Europe)
- Cees Hertogh (Netherlands)
- Iva Holmerová (Czech Republic)
- Sabine Jansen (Germany)
- Kati Juva (Finland)
- Mary Marshall (United Kingdom)
- Celso Pontes (Portugal)
- Michael Schmieder (Switzerland) and Sigurd Sparr (Norway).

In addition, representatives from the German Ministry of Health and national representatives from Belgium and Luxembourg (Magda Aelvoet, Christian Berringer, Malou Kapgen, Cornelia Reitberger und Matthias von Schwanenflügel) attended and supported the meetings of the ethics network.

The aim of the network was to carry out an in-depth literature search on identified priority areas and develop a report with the findings. In 2010, the network paid particular attention to the ethical implications of the use of assistive technologies in home and institutional settings. A working group was set up comprised of a person with dementia, a carer, representatives of Alzheimer associations and researchers and ethicists with an interest in the field. The working group was made up of the following experts:

- Dianne Gove (Alzheimer Europe)
- Inger Hagen (Norway)
- Sirkkaliissa Heimonen (Finland)
- Stefánia Kapronczay (Hungary)
- Heike von Lützau-Hohlbein (Germany)
Alzheimer Europe organised two meetings of the Dementia Ethics Steering Committee and the working group on assistive technologies.

The work resulted in a report which presents the position of Alzheimer Europe and guidelines on the ethical use of assistive technology for/by people with dementia and proposes an ethical framework for decision making. A brief overview is provided of the three main issues of importance, namely dementia, assistive technology and ethics. This is followed by a discussion of the various ethical issues linked to the use of assistive technology which addresses not only possible disadvantages and ethical dilemmas but also looks at the positive implications of the use of assistive technology and how it can contribute towards respecting certain ethical principles with regard to people with dementia.

2.3 Deliverables

The following deliverables resulted from the work of the European Dementia Ethics Network in 2010:

- Alzheimer Europe website section on ethics

As part of the ethics priority, Alzheimer Europe dedicated a complete section of its website to a discussion of ethical issues in dementia care and treatment. The section contains an in-depth presentation of various ethical principles (autonomy, beneficence, non-maleficence, justice, equity, solidarity, dignity) and their application to specific situations in dementia care and treatment (advance directives, involvement of people with dementia in research, restrictions of freedom and end-of-life care).

In collaboration with Visual Online, the service provider in charge of the Alzheimer Europe website, Alzheimer Europe also developed a platform which will allow information on the website to be included in different languages, as the long-term objectives of the ethics project is to present information in other European languages. Also, a discussion forum was integrated on the Alzheimer Europe website to allow users of the website to discuss ethical issues and to propose specific issues for discussion to the Ethics Advisory Board.

The ethics section of the Alzheimer Europe website can be found at: http://www.alzheimer-europe.org/Ethics.

- Report on the ethical implications of assistive technologies

The report examines the ethical issues linked to the use of assistive technology for/by people with dementia. It contains a brief overview of the three main issues of importance, namely dementia, assistive technology and ethics. This is followed by a discussion of the various ethical issues linked to the use of assistive technology (based on an extensive review of the literature) which addresses not only possible disadvantages but also looks at the positive implications of the use of AT and how it can contribute towards respecting certain ethical principles with regard to people with dementia.

In the document, Alzheimer Europe also presents its position and guidelines on the ethical use of assistive technologies for/by people with dementia and proposes an ethical framework for decision making. The publication is targeted at a wide audience including people with dementia, carers, health and social care professionals, service providers, AT designers, researchers and policy makers.

Copies of the report are annexed to this final report.
2.4 Annex 1: Ethics section on AE website

2.4.1 Definitions and different approaches

2.4.1.1 What is meant by the term ethics?

Broadly speaking, ethics is a branch of philosophy which seeks to address issues related to concepts of right and wrong. It is sometimes referred to as moral philosophy and can be broadly divided into four subject areas which are as follows:

- Meta-ethics aims to understand the nature of ethical evaluations, the origin of ethical principles and the meanings of terms used but is value-free.
- Descriptive ethics involves, for example, determining what proportion of the population or a certain group considers that something is right or wrong.
- Normative ethics, sometimes referred to as moral theory, focuses on how moral values are determined, what makes things right or wrong and what should be done.
- Applied ethics examines controversial issues (such as euthanasia, abortion and capital punishment) and applies ethical theories to real life situations. Applied ethical issues are those which are clearly moral issues and for which there are significant groups of people who are either for and against. Often there is no simple answer as to whether something is right or wrong as ethical issues tend to be multi-faceted. Possible solutions may appeal to some ethical principles and not others, just as they may benefit certain groups of people and not others.

- medical and nursing ethics (considers moral values and judgements linked to medicine and nursing)
- bioethics (considers ethical issues which arise in connection with the advances in biology and medicine) – medical ethics and bioethics are closely linked and there is sometimes overlap between the two

In their attempt to define ethics, Verlasquez et al. (1987) drew attention to four things that should not be considered as ethics.

1. They suggest that ethics is not necessarily about acting in accordance with one’s feelings as sometimes a person’s feelings about a particular issue may lead them to act in a way that is unethical.
2. Ethics cannot be equated with religion because although most religions advocate and provide incentives for people to act in an ethical manner, ethics applies to everyone whereas religion is limited to certain groups of people.
3. Behaving in an ethical manner should not be confused with respecting laws as throughout history examples can be found of laws which with hindsight were clearly unethical (e.g. linked to slavery, apartheid and compulsory sterilization of certain groups of people). Even nowadays there are laws which authorize capital punishment, euthanasia, abortion and compulsory electroconvulsive shock treatment even though large sections of the population are against such practices.
4. Finally, ethical behaviour cannot be based on “what society accepts” because people’s behaviour may deviate from what is ethical and societies may condone unethical behaviour (such as withholding vital medical treatment from certain groups of people or even trying to eliminate certain groups of people altogether). In this sense, society is understood as state actions or decisions that are more or less supported or tolerated by citizens. However, whole populations are seldom if ever all in agreement on ethical issues. If by “society”, the whole population is intended, then it would be necessary to carry out a survey to find out what they think about each ethical issue and as people tend to be divided on numerous issues, this would be impractical and inconclusive.

2.4.1.2 Medical ethics and bioethics in Europe

The term “medical ethics” is often used to refer to the deontology of the medical profession covering issues such as moral rules, rules of etiquette and rules for professional conduct. The word “deontological” comes from the root “deon” which means duty or obligation in Latin. In some countries,
codes or medical ethics have been supplemented by patients’ rights laws. There is a difference between the two in that the former emphasizes the obligations and duties of doctors whereas the latter usually involves some form of legal right or entitlement. Nevertheless, in some countries codes of medical ethics are enshrined in law and consequently take on a legal status (with regard to the obligations of healthcare professionals). Hoy (2004) argues that obligations which are enforced and hence not undertaken freely, are not in the realm of the ethical. For example, in countries where slavery has been abolished or certain forms of animal experimentation made illegal, such issues move from the realm of the ethical to that of the legal. On the other hand, certain practices such as abortion or euthanasia have been legalized in some countries but are not accepted some groups in society as being ethical.

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

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

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

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

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

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

2.4.1.3 The American influence (the four common bioethical principles)

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

“European authors tend to emphasize the social and cultural context of many ethical debates. They are focusing attention on the structure and organisation of the health care system, as well as the network of social values in which the moral problems are presented. They criticize the individualistic focus of dominant bioethical discourses and the relative negligence of community values, interpersonal relationships and solidarity. Individualistic ethics in their view should be complemented with social ethics.” (Ten Have, 2001, p. 8)

2.4.1.3.1 Respect for autonomy

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

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

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

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

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

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

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

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

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

However, it should be borne in mind that not everyone agrees with the emphasis that is currently placed on autonomy. For example, although the Danish Council of Ethics (2003) appreciates individuals taking responsibility for their own lives, it points out that the ideal of personal autonomy is based on extreme individualism and that this viewpoint takes the focus away from the fact that people are always influenced and to some extent dependent on others. They are what they are as a result of interactions with others and a particular history. Similarly, the Finnish National Advisory Board on Health Care Ethics - ETENE - (2001) cautions against concentrating almost exclusively on the principles of autonomy and self-determination. Whilst these principles may serve to protect patients from abuse and give them an active role in their treatment, ETENE states,
“...it is important to understand that help for a human being cannot be based on just a single, isolated principle – and far less on its mechanical application. Alongside self-determination, the principles of the common good, community and equity, among others, demand to be taken just as seriously.”

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

2.4.1.3.2 Beneficence and non-maleficence

As the principles of beneficence and non-maleficence are closely related, they are discussed together in this section. Beneficence involves balancing the benefits of treatment against the risks and costs involved, whereas non-maleficence means avoiding the causation of harm. As many treatments involve some degree of harm, the principle of non-maleficence would imply that the harm should not be disproportionate to the benefit of the treatment. Respecting the principles of beneficence and non-maleficence may in certain circumstances mean failing to respect a person’s autonomy i.e. respecting their views about a particular treatment. For example, it may be necessary to provide treatment that is not desired in order to prevent the development of a future, more serious health problem. The treatment might be unpleasant, uncomfortable or even painful but this might involve less harm to the patient than would occur, were they not to have it.

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

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

2.4.1.3.3 Justice

The principle of justice 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). Alperovitch et al. (2009) describe two elements of the principle of justice, namely equality and equity.

The right to be treated equally, and in some cases equal access to treatment, can be found in many constitutions, but in actual practice, a number of different factors may influence actual access to treatment e.g. age, place of residence, social status, ethnic background, culture, sexual preferences, disability, legal capacity, hospital budgets, insurance cover and prognosis. The Swiss Academy of Medical Sciences recently reported that doctors and other medical staff are increasingly refusing to administer potentially useful treatment for economic reasons (SAMS, 2008) and there has been considerable debate in the UK over the refusal of expensive treatment to patients who would benefit from it (need reference here).

With regard to equality in the provision of care, some people are not treated with the same degree of respect as that accorded to others e.g. with indifference, unfriendliness, lack of concern or rudeness. Such attitudes, prejudice and discrimination may, in some cases, be a reflection of the stigmatization of
people belonging to groups identified and devalued on the basis of a particular attribute (of which dementia is one example). Inequality and discrimination may also be based on structural violence such as racism, sexism and poverty (Mahajan et al., 2008) which Kelly (2006) describes as a form of discrimination based on unequal power relations.

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

Nevertheless, it is possible that a high degree of incapacity and increased vulnerability, perhaps combined with failure by others to recognise their personhood, may result in a lack of distributive justice. Nerney (undated) argues:

“Once individuals get reduced to a status where personal autonomy or self-determination is not "possible", they may lose their moral claim on our resources. Contemporary ethicists (…/…) make this claim on the principle of distributive justice. Distributive justice underlies our progressive tax system, e.g., and simply calls for sharing resources in ways that approximate fairness. Distributive justice has been the cornerstone upon which we argued for resources for the most vulnerable. Contemporary ethical theory has now turned this principle on its head. Because we live in times of scarce resources, especially medical and long term care resources, those who can "benefit" the least (read those with significant disabilities) may end up having the lowest moral claim on these resources.”

2.4.1.4 Other ethical principles

2.4.1.4.1 Solidarity and interdependence

Alperovitch et al. (2009) link the principle of solidarity to those of justice and equity explaining that in order to ensure equal access to support, some degree of solidarity may be needed. They emphasize the recognition of the individual value of each person and the need to help those whose dignity is endangered (see section on dignity). Solidarity, in the social sense, can be described as a kind of voluntary union or fellowship amongst people (e.g. groups, classes, nations etc.) based on a community of feelings, purposes, responsibilities and/or interests, whereby in the spirit of cooperation, people are concerned about those who are less fortunate or vulnerable and strive for equity and justice for all. This may result in specific action to help people who are disadvantaged or vulnerable such as policies to counter social discrimination. Sometimes, people may contribute towards the support of more needy individuals through the payment of obligatory social charges or sickness fund contributions without having any desire to provide solidarity as this may simply be the State system. The principle of solidarity differs to that of subsidiarity which in relation to social welfare, for example, would imply that people should take care of themselves and only if they are unable to do so, should turn to their families and then, if necessary, to communities, local governments and eventually state governments (Kain, 2009).

Solidarity may be based on notions of interdependence which involves mutual and physical responsibility to others and the sharing of a common set of principles, which is often linked to devotion to one’s family or community. Hockey and James (1993) suggest that the discourse of dependency, which has the greatest impact on children and old people, especially elderly people affected by dementia, ignores the interdependence of all people and the fact that dependency on others for support can occur at any stage in the life continuum by people who are ill or well. This means that during a person’s lifetime, autonomy may take a more central place than the need for solidarity and vice versa, although both may be present at the same time. A person may be dependent on others for certain things but still be able to take part in the decision-making process surrounding the provision of such assistance and for other matters in his/her life. In some cases (e.g. in the case of pandemics), people may be torn between the principles of autonomy (e.g. the desire not to be vaccinated due to personal fears about risks involved) and solidarity (the desire not to spread a disease to others).

However, the polarisation of the concepts of independency and dependency serves as a means to demarcate certain groups of people, such as people with dementia, and may contribute towards their
loss of power and devaluation. They may sometimes be perceived by others and even themselves as not contributing and being a burden to the state and society. Drawing on disability studies, Adams (2008) questions whether independence means the same thing to disabled people as it does to the non-disabled and suggests that control over their lives might be more important to disabled people than actual ability to do things.

2.4.1.4.2 Personhood

The way that people understand and relate to each other contributes towards the acknowledgement or development and maintenance of personhood. Nevertheless, being an actual person in the first place is important and determining what or who is a person involves setting boundaries (Baldwin and Capstick, 2007). Where someone falls in relation to those boundaries will determine whether s/he is considered a person or a “non-person”. For some theorists, particularly ethicists, this means possessing certain capacities. Others would argue that personhood more or less equates with simply being a human being, whereas the role of interaction with others has also been highlighted, as has the importance of the physical body. The following approaches to personhood will be considered in this section, and a few examples provided of research into perceptions of personhood:

1. inherent/transcendental personhood
2. capacity-based approach to personhood
3. interpersonal theories of personhood
4. the body
5. empirical research into perceptions of personhood

• Inherent/transcendental personhood

Being human has been equated with being a person in the sense that being-in-itself is the only criteria. Kitwood (1997) claimed that personhood was sacred and unique and that every person had an ethical status and should be treated with deep respect. (He also later emphasised the relational aspect of personhood but this is not necessarily contradictory.) In some religions and according to certain spiritual beliefs, people have a kind of unique inner essence which may even be believed to continue beyond human life (e.g. through reincarnation or an after-life). The belief in a kind “non-material soul that still exists intact underneath all the neurological losses of dementia” (Post, 2006, p.231) may provide solace to carers and help ensure that interaction with the person is maintained. However, a belief in the inherent personhood of people (including those with dementia) does not necessarily guarantee that they are treated humanely and with respect. Moreover, some people believe that a person’s essence or soul may be lost or no longer possible to reach, as reflected in statements made by carers in a recent small-scale qualitative study:

“But you have to remember, that body is not who the person is. The person is gone”
“There’s no sense is asking her…. She’s not there…” (Dunham and Cannon, 2008, p. 49)

Not everyone has religious or spiritual beliefs and even those who do, within the same religion or philosophy of life, may differ greatly with regard to what they believe and the strength of that belief. However, the main issue is not to determine which religion has “got it right” or whether people really have an innate, unique essence or soul but rather to understand how some people define personhood and to recognise that this may be influenced by their spiritual or religious beliefs. It could even contribute towards fear of dementia in that their worst mental image of what dementia might resemble is applied to a human being. Some people might find it more reassuring to believe that the person is “no longer there”.

• Capacity-based approach to personhood

For Kant (and others since, e.g. Cooley, 2007; Dan Brock, 1993), to qualify as a person, it was necessary to possess rationality (the ability to think and reason logically) and to be able to communicate this to other people. It is clear from this definition that many people with dementia who have difficulty with logical thought and reasoning and/or difficulty communicating this to others would not meet the selection criteria for personhood. Another example of a capacity-based approach is that of Warren (1973) who defined six criteria for personhood, namely consciousness, reasoning, self-motivating activity, capacity to communicate, presence of self-concept and self-awareness.

For yet others, the capacity to perceive oneself as existing over time is considered important (Buchanan, 1988; Kuhse, 1999; Parfit, 1984). Dan Brock (1993), for example, argues that people with
severe dementia, whilst members of the human species are worse off than animals in some respects in that they have no capacity for integrated and goal-directed behaviour and that due to memory loss cannot forge links across time that establish a sense of personal identity across time. He concludes that they lack personhood (Baldwin and Capstick, 2007).

Some people have a feeling that a person with severe dementia is no longer a person or at least not the person they once were, even though they are still alive (Matthews, 2006). Parfit (1984) claimed that people can have current and former selves which are linked by varying degrees of psychological continuity, and that there may come a time when the psychological continuity between the two is so great that one should consider the person as no longer being the same person. Some go even further suggesting that there may come a time when a person no longer has any kind of continuity with people in general and that such people are in effect “non-persons” (Buchanan, 1988). Tooley (1983) further argues that the ability to see oneself as extending over time is a necessary condition for being a person and for having a right to life. Clearly, there is sometimes a tendency to erroneously associate the loss of cognitive abilities with the loss of the quality of being human (Blanchard, 2006).

However, even if other people need to be able to recognise personhood in an individual, this does not necessarily imply that the latter has to have the ability to communicate it (Grobstein, 1981). The hypercognitive definition of personhood – as Post (2006) calls it - fails to take into account the emotional and relational needs and capacities of people with dementia (Kitwood and Bredin, 1992; Post, 2006; Rudman, 1997 – in Post, 2006). It neglects the more social, expressive, imaginative and even unconscious dimensions of being human (Crisp, 1999), which nevertheless generally require some degree of reasoning and memory. Finally, it overlooks the importance of social interaction in that a person who lacks certain capacities may be considered a non-person with the result that meaningful interaction with that person may cease and this will contribute towards further loss of capacity.

- Interpersonal theories of personhood

Despite certain religious and spiritual beliefs about people having a unique essence or soul, which might be understood as reflecting a concept of innate personhood, it is interesting to note that early Christianity differentiated between the terms “individual” and “person”, whereby the latter was understood as referring to the individual in relationship to others (Allen and Coleman, 2006). The following descriptions of personhood also reflect a relationship-based understanding of personhood:

- “who one is and who one can be are defined in the context of authentic relationships” (Malloy and Hadjistavropoulos, 2004, p.152)
- “It is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust” (Kitwood, 1997, p.8)
- “rooted in relationships with others and therefore requires the presence of another human being” (Penrod et al., 2007, p.64)
- “a dynamic concept, refined and articulated through constructs and subsequent social intercourse” (Jenkins and Price, 1996, p.88)
- a status accorded to one human being by another (Moody, 2003)

If personhood is constructed and maintained in a social environment, people with dementia may find themselves in a vulnerable position due to their progressive difficulty engaging socially and effectively with others. This may lead to their gradual withdrawal from social contact with the result that other people may distance themselves from them, thereby resulting in isolation, social exclusion, increased vulnerability and possibly, further deterioration of their condition.

Kitwood not only provided a model of dementia which highlights the interaction between neurological impairment, the psychology of the person with dementia and the social environment, but also strongly advocated for the respect of the personhood of the person with dementia. He explained that people with dementia are not simply biological entities or the bearers of the condition but people who are at risk of losing their personhood. His concept of personhood was influenced to some extent by the work of the German philosopher Martin Buber (1878-1965).

Buber (1970) identified two different ways that people relate to one another, which may be of relevance to the maintenance of personhood in people with dementia. These two ways are described through the word pairs “I-It” and “I-Thou” (later translated to I-You”). The I-It mode of relating is one in which a person relates to the other in a cool, distanced, non-involved way which fails to fully acknowledge the individuality of the other as the other is objectified. The I-Thou mode of relating, in contrast, involves meeting the other person in a genuine human exchange. With reference to the I-Thou relationship,
Barich (1998) states, “You become a person (as opposed to an alienated and isolated individual) when you enter into relation with people.” If people with dementia are objectified through an I-It mode of relating, their link to the outside world is threatened and perhaps damaged, especially when they themselves have lost the capacity to install and actively encourage an I-Thou form of relating. Buber’s concept was linked to religion in that it was intended to describe how humans can enter into a relationship with God through their relationships with others but this should not lessen its relevance to the debate about personhood.

A common feature of all human interaction is turn-taking/turn-making. This occurs even before infants have acquired language through “protoconversations” between caregiver and infant whereby the caregiver is attuned to and responds to the gestures and bodily rhythms of the infant in a process of mirroring, echoing and resonating (Stacey, 2003, p137). Caregivers often act as if the infant’s sounds and gestures were purposeful and meaningful, and take a key role in supporting and maintaining the interaction. This lays the foundations for purposeful interaction on the part of the infant and the development of a sense of self. The actions and attitudes of the caregivers towards the infant reflect a belief in the personhood of the infant. In this way, the adults relate to the infant not in the I-it form (i.e. as if the infant were an object) but in the I-Thou form. The caregivers are in a position of power as they could ignore the infant’s actions and take the stance that s/he is not capable of interaction. This may happen in some cases, but eventually the child will develop language and start interacting with the outside world and his/her personhood will be acknowledged and confirmed through interaction.

In the case of dementia, the same degree of understanding and tolerance is less common. Unlike the infant who is considered to be in the process of developing the capacity for meaningful communication with the support of adults, people with dementia are often considered as having had this capacity and lost it (which may reflect a capacity-based approach to personhood). Nevertheless, they also need additional support from others at some point in time to maintain contact and share meaningful interaction (in the I-Thou mode of relating) so as to benefit from social inclusion and maintain their sense of personhood. People with advanced dementia may have difficulty communicating in ways that other people are willing to accept as meaningful. If other people do not consider their utterances and behaviour as valid forms of interaction and are not motivated to take on a more supportive role in the interaction, then turn-taking breaks down and people with dementia gradually becomes objects to which personhood is no longer accorded. Grobstein (1981) claims that the central criterion of personhood is that it can be recognised by others. If so, people who have difficulty communicating their personhood (e.g. newborn infants, people in the last stage of dementia and people who are unconscious) are dependent on others to recognise it.

The concept of personhood has also been linked to the different selves that a person may have. Sabat (2001) described three different selves: 1. the self of personal identity (expressed through sentences using “I” such as “I feel, I think etc.”); 2. the self comprised of the attributes a person possesses and 3. the self consisting of the social self or personae presented to others (e.g. through social roles). People who have dementia gradually lose the ability to maintain their social roles without necessarily having the opportunity or capacity to take on alternative, valued social roles, particularly as doing so depends on mutual recognition and cooperation, and more fundamentally, recognition of their personhood. (note: insert something here about studies indicating that people losing social roles does not necessarily imply loss of all notion of self)

Kitwood argued that there were two aspects to the person (i.e. the adapted self and the experiential self). The adapted self and the experiential self represent two different ways of being. The former is described as “highly and tightly socialised, particularly in relation to the performing of given roles” (Kitwood, 1997, p. 15). The latter arises out of simply being with people within a context of equality and mutual respect and attention. The experiential self may persist throughout life until death provided that the right conditions are provided. According to Kitwood, the I-Thou form of relating described by Buber, provides the ideal framework for preserving and enhancing this aspect of personhood.

Perceptions of personhood may differ according to the stage of life. According to Kitwood and Bredin (1992, p.275), “In an ethical sense, personhood is attributed even to the newborn infant. In an empirical sense, personhood emerges in a social context.” Myser (2007) contrasts the terra incognita of the infant (a kind of developing personhood, imagined and projected by carers), with terra cognita of the adult (full personhood co-constructed with other members of society) and finally of “fading personhood” (in constant need of being re-constructed and restored with the assistance of carers and society).

The following extract highlights the relational aspect of personhood and the perceived duty for people who come into contact with a person with dementia to look for the person and not just at the dementia:
“Being a “person” is the fundamental philosophical and sociological position of a human being, with value, intelligence, a history and a present. The challenge in dementia is to continue to seek for and not to dismiss that person.” (Lawrence, 2007, p.555)

4. The body

Descartes described a split between mind and body, whereby the substance of each was separate and distinct. Whereas the body was considered as having a material form, the mind was deemed unlocatable. According to the situated-embodied-agent view (Hughes, 2001 – in Moody, 2003), personhood is maintained or bestowed on a particular person whose human existence is linked to a physical body in a particular familial, cultural and historical context. Based on Heidegger’s notion of Dasein (being-there), Merleau-Ponty (2002) developed a concept which is now often referred to as the body-subject implying that every human has a body (being a physical creature) and is capable of thought, reflection and communication. These two parts are not separate as in Descartes body/mind dualism but rather a unified form which experiences the world and expresses itself in a bodily form. When a person sees, s/he is dependent on the eyes but there is an “I” behind the eye. As dementia progresses the person can no longer rely on the unified form. Consciousness is expressed through bodily activity but the body, as a vehicle for expression, is breaking down. This does not mean that there is no consciousness [check ref].

At a more psychological than philosophical level, Jenkins and Price (1996) draw attention to the way that people tend to make analogies between their bodies and elements or aspects of everyday life (e.g. viewing their body as a home, servant or vehicle). When the body starts to let the person down and the unified form fails to function, the body might start to be seen as a traitor, an enemy or a prison. The way that a person perceives the body of someone with dementia (e.g. an empty shell, prison etc.) might affect the way they relate to them. Such analogies may conjure up powerful images which may in turn influence and even serve to justify certain negative modes of relating which are detrimental to the recognition and maintenance of personhood.

5. Empirical research into perceptions of personhood

Kitwood challenged the capacity-based view of personhood drawing attention to evidence from case studies provided by Mills and Coleman (1994, p.213 – in Downs, 1997) which suggests that people with dementia retain a personal awareness of their individual uniqueness of being until death. He also highlighted the work of Sabat and Harré (1992) based on interviews and observation of 3 people. They concluded that it is the social and public self that is lost in severe dementia but not the private sense of self (Downs, 1997). These studies were extremely small scale but perhaps suggest that the way that people define or understand personhood may affect whether or not they find it. For example, a person might walk through a field of dandelions and claim that they saw no flowers as they consider dandelions as weeds.

Personhood is an elusive thing which cannot be easily measured. However, it is possible to investigate people’s beliefs about it. Myser (2007) carried out ethnographic research with 250 healthcare professionals and carers between 1988 and 1990 in Sweden, India and the United States of America in a variety of settings. One of her aims was to examine the ethical concept of personhood as perceived by healthcare professionals and lay people. She identified seven key themes:

1. Emphasis on abilities and potential more or less unique to human beings (e.g. logical thought and reasoning) and importance of people being able to communicate these abilities in such a way that other people can recognise them.

2. Ability to relate to other people (involving self-awareness and ability to communicate capacities)

3. Aesthetic aspect of personhood (example given: ....“if a patient looked like a distorted frog or monster, the patient might not evoke feelings of sympathy or empathy and therefore might not be recognized as having moral status or personhood....” p. 56)

4. Possession of additional capacities/human qualities (including intellectual, emotional, relational and moral capacities). A superior intellect in the absence of “human qualities” would not be considered as reflecting personhood. [I wonder if they had in mind the possibility of aliens]

5. “Speciesism” grounded in the “instinct” to identify with and value people in our own group (which might include severely handicapped people if part of “our own particular group”).

6. Status cues and the extent that a person is perceived as being wanted by others.

7. The concept of a continuum whereby personhood evolves over time through contact with the person concerned and through the development of empathy and the creation of relationships.
The above themes represent how personhood is perceived by those who were interviewed and is not an argument for viewing personhood in that particular way. However, it reveals the way that personhood is seen as something that arises out of social interaction. Each of the themes is linked in some way to interaction between people, or at least to how people understand each other. This combined philosophical and psychological understanding of personhood combines both ethical and psychosocial elements.

2.4.1.4.3 Dignity

References to and definition of dignity

References to the right to and protection of dignity or human dignity can be found in several national, European and international conventions and charters as well as in several constitutions and national laws. Examples include the Charter of the Fundamental Rights of the European Union and the Convention on Human Rights and Biomedicine. According to the former, people have a right to life, to integrity of the person, not to be subjected to slavery or forced labour, and not to be tortured, degraded or humiliated (Holmerova et al., 2007). Some of these aspects of dignity may be interrelated. For example, Caplan (2010) argues that people may be repulsed by torture as it often involves humiliation or degradation.

However, the concept of dignity is difficult to define (Holmerova et al., 2007; Horton, 2004; Marmot, 2004). There have even been claims that it is a meaningless slogan and a useless concept in bioethics which can be reduced to issues surrounding respect for individuals and autonomy (Macklin, 2003 in Caplan, 2010). Moreover, there is considerable overlap with the concept of personhood in the sense that opinions differ as to whether it is an innate quality of human beings or something that is granted or attributed to a person which prompts a few questions such as:

- Is dignity a property of an individual or of the way others react to him or her?
- Can one’s dignity be affected by the way one is treated? (Marmot, 2004)
- Can dignity be inalienable but at the same time something that can be lost or destroyed? (Jacobson, 2007)

The answers to these questions are unclear as there are competing definitions of dignity and as Holmovera et al. (2007) point out, it is often easier to define what constitutes a violation of dignity than to provide examples of what dignity is. Jonathan Mann, for example, divided violations of dignity into four categories: 1. being ignored or insufficiently acknowledged; 2. being seen but only as a member of a group; 3. having one’s personal space transgressed involuntarily; 4. humiliation (quoted in Horton, 2004).

Nevertheless, there have been several attempts to define dignity. It has been described as:

- something that is irreducible, transcending political, economic and cultural difference, that has been conferred on humans by God and that is “the moral basis of our shared humanity, and thus ultimately of universal human rights” (Sacks, 2002)
- based on the ability to exercise will and choice (Pico della Mirandola, 1468)
- “(an absolute inner worth) by which he exacts respect for himself from all other rational beings in the world” (Kant, 1797)
- an inherent characteristic of being human, it can be subjectively felt as an attribute of the self, and is made manifest through behaviour that demonstrates respect for self and others (Jacelon et al., 2004)
- the maintenance of social conventions and decorum, and the right (and duty) of autonomy and self control (Caygill, 1990)
- the public worth of man (Hobbes, date)
- strength, both of mind and body (Wollstonecraft, 1792 – on the definition of true dignity and human happiness)

Based on an extensive review of the literature, Jacobsen (2007) summarised some of the different and seemingly contradictory ways that dignity has been perceived by different authors, for example as an objective phenomenon and a subjective phenomenon, something that is intrinsic as well as extrinsic, unconditional and static but also contingent and dynamic, inherent but also bestowed on a person or achieved. A range of appellations were also noted such as basic dignity, human dignity, social dignity and personal dignity which can also be confusing but Jacobson (2007) claims that these can be condensed into two main concepts, namely human dignity and social dignity. This classification into two related concepts might also add some clarity to these seemingly contradictory properties of various conceptualizations of dignity.
Human dignity

Human dignity (sometimes referred to using the German term Menschenwürde) refers to the inherent and inalienable value of every human being which cannot be destroyed, taken away or measured. It is not dependent or conditional on anything. It simply results from being human and can refer to individuals, groups or people as a species. There are two approaches to understanding human dignity, one which is religious and one which is secular. The former is based on a belief that humans have a special place in the world as we know it and that human life is sacred. The following extracts, taken from documents linked to the Catholic Church, provide examples of this:

“215 Whatever the progress in technology and economic life, there can be neither justice nor peace in the world, so long as men and women fail to realize how great is their dignity; for they have been created by God and are God's children. Mater et Magistra, (Christianity and Social Progress), Encyclical Letter of Pope John XXIII, 1961

“11 Human persons are willed by God; they are imprinted with God's image. Their dignity does not come from the work they do but from the persons they are. Centesimus Annus, (The Hundredth Year), Encyclical Letter of Pope John Paul II, 1991

“At the centre of all Catholic social teaching are the transcendence of God and the dignity of the human person. The human person is the clearest reflection of God's presence in the world; all of the Church's work in pursuit of both justice and peace is designed to protect and promote the dignity of every person. For each person not only reflects God, but is the expression of God's creative work and the meaning of Christ's redemptive ministry. The Challenge of Peace, United States Conference of Catholic Bishops, 1983”

(Source: Eastern Ontario Catholic Curriculum Cooperative, 2005)

The secular approach to human dignity tends to be associated with Kantian and neo-Kantian philosophy which emphasizes rationality and the ability of humans to act as moral agents, as well as equality and the need to treat people with respect. However, it could be argued that dignity cannot be reduced to a question of autonomy as very young children or people with mental incapacity would be excluded (Bostrom, 2008).

Social dignity

Social dignity can also be divided into two categories: dignity-of-self and dignity-in-relation (Jacobson, 2007). Dignity-of-self encompasses a sense of gravity, decorum, self-respect or self-confidence which can be fostered and promoted but can presumably also be lost. It emerges through social interaction in a particular social context (i.e. in a historical context, place and time).

Dignity-in-relation describes the way that a person's perceived value and worthiness is reflected back within the context of interaction. Dignity-of-self is to a large extent dependent on what is reflected back by other people with whom one comes into contact based on their perceptions of one's words or actions. Those who have achieved social dignity may be rewarded by signs of respect but social dignity can be withheld, lost, threatened, gained, maintained, bestowed or achieved.

Some authors recognize the two different types of dignity. Caygill's (1990) definition of dignity as the maintenance of social conventions and decorum, and the right (and duty) of autonomy and self control seems to combine the concept of social dignity with that of secular human dignity. Similarly, Kolnai described two types of dignity. The first, “human dignity” was linked to being a person and the second, “dignity as a quality” was comprised of three main characteristics: 1. composure and restraint, 2. distinctness and invulnerability, 3. serenity with power of self-assertion which is not limited to people as it could also apply to animals, landscapes and even works of art (Bostrom, 2008; Holmerova et al., 2007).

In the context of dementia, social dignity may be threatened as communication difficulties lead to a gradual breakdown in verbal communication and in many cases a reduction of meaningful interaction. This in turn may threaten personhood and consequently human dignity if the person ceases to be considered truly human. For this reason, when a person has severe dementia the onus should be on friends and carers to take over responsibility for maintaining communication and social interaction with him/her.
2.4.1.5 Cultural issues linked to bioethical principles

It could be argued that the bioethical principles described by Beauchamp and Childress reflect 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 wellbeing 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 Kennel-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.

2.4.2 Ethical issues in practice

2.4.2.1 Ethical principles in relation to advance directives and personhood

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

2.4.2.1.1 Dworkin – the importance of critical interests

The evidentiary vs. the integrity view of autonomy

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

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

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

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

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

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

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

Beneficence

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

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

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

Dworkin’s position on dementia and personal identity

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

2.4.2.1.2 Derek Parfit – the psychological view of personal identity

Parfit takes the view that personal identity is constituted over time by varying degrees of continuity between former and later selves in terms of a wide range of psychological and physical features. The psychological aspect of personal identity is constituted by the degrees of similarity between two temporally separate selves with regard to a person’s personality, belief structure and desires, which may in certain cases (such as advanced dementia) depending on the degree of similarity and continuity, move from being intra-personal to being inter-personal.

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

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

2.4.2.1.3 Dresser – respecting a person’s current subjective experience

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

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

Nevertheless, such an approach might not be possible in all countries. In Germany, for example, two of the three propositions laid down in the Principles of the German Medical Association concerning terminal care (1998), are the refusal of any medical assessment of the value of life or the quality of life by doctors and the respect for patients’ wishes, including those made in an advance declaration (in Wegener, 2000)

2.4.2.1.4 Robertson - discontinuity of interests

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

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

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

2.4.2.1.5 Buchanan - psychological continuity and personhood

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

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

2.4.2.1.6 Kuhse – existence over time

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

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

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

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

2.4.2.1.7 Remarks re the personal identity and advance directives debate

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

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

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

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

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

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

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

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

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

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

2.4.2.2.1 Balancing potential risk and autonomy

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

In addition to general conditions governing the participation of people in research, the Convention on Human Rights and Biomedicine1 (article 17) has conditions which must be met before people who are unable to consent can participate2. These are that:

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

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

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

This last condition is fairly restrictive and rules out certain procedures, which could be particularly useful. Positron emission tomography (PET) scans, for example, can be viewed as having greater than minimal risk for people with dementia because 1. they are invasive, 2. they carry the risk of pain and discomfort during and after, and 3. complications can require surgery to correct (Berghmans, 1998).

More recently, the International Ethical Guidelines for Biomedical Research Involving Human Subjects (2002)3 allows slightly more flexibility with regard to risk when research involves individuals who are not capable of giving informed consent, including vulnerable groups such as those with varying degrees of dementia. Guideline 9 states:

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

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

2.4.2.2.2 Consent to research

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1 Council of Europe (1997), The Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine, Oviedo, 4.IV.1997

2 On 30 June 2004, the Committee of Ministers adopted an Additional Protocol to the Convention on Human Rights and Biomedicine on Biomedical Research. It will be opened for signature early in 2005. Details of the Additional Protocol are available at: www.coe.int/bioethics

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

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

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

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

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

Consequently, in order to have a sufficient number of subjects for non-therapeutic research involving people with dementia, it is necessary to talk to the potential subjects about it whilst they are sufficiently capable of making a decision. Unfortunately, many people are only diagnosed with dementia at a later stage when they are not sufficiently able to understand what is involved and what the implications might be of making such an advance directive. Finding out that one has dementia is often a time a worry and stress, which for some people might not be the best time to start thinking about taking part in research projects. People with dementia would perhaps be more willing to take part in experimental treatment if treatments of proved efficacy have not had the desired effect. Unfortunately, by that time, they might not have sufficient capacity to consent or to write an advance directive (Lötjönen, 2003).

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

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

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

2.4.2.3 End-of-life care and decision making

2.4.2.3.1 Balancing potential risk and autonomy

Autonomy and capacity

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 State 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, health care proxies and carers. If the person with dementia has expressed a wish to be cared for at home, fulfillment 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.

In the debate over assisted suicide and euthanasia dignity is often associated with the exercise of autonomy (i.e. maintaining control over the process of dying). However, considering dignity as being closely associated with autonomy would imply an absence of dignity for people lacking the necessary capacity to take autonomous decisions. On the other hand, whilst control is emphasized by those in favour of “dying with dignity”, another aspect might be the feared loss or deterioration of dignity associated with a certain stage of disease or dependency on others (which might be experienced in the absence of control over the dying process).

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.

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.

2.4.2.3.2 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).

2.4.2.3.3 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.

2.4.2.3.4 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.

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

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

2.4.2.3.5 Emphasis on healing as opposed to accompanying the terminally ill

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

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

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

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

In the framework of its Lawnet project (2000), Alzheimer Europe and a group of experts from the domain of old age psychiatry, law and ethics (including a person with dementia and carers) formed a discussion group and drafted guidelines on the use of various measures designed to restrict liberty of movement (including the use of restraint). These guidelines, which can be found below, were intended to serve as a starting point for discussion at national level.

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

Care should allow for some degree of risk taking. Therefore, a balance should be achieved between the adult's personal autonomy and the use of restraint as a means of care and/or protection.

The restriction of an adult's liberty of movement should be avoided as far as possible. If restraint is deemed necessary, the adult's behaviour should be assessed in order to try to determine why the measure proved necessary. Attention should be paid to possible contributing factors such as pain, discomfort, side effects of drugs, psychological stress, poor relationships and incompatibility between the adult and his/her carers etc.

If no remedial cause can be found, the risk of not restraining the adult should be considered. S/he should only be restrained if the risk is considered to be unacceptable, i.e. the consequences of not applying restraint would be detrimental to the adult's wellbeing (medical, psychological or other) and that the benefits of doing so outweigh any possible negative outcome.

Whenever possible a multidisciplinary team should be involved in decisions about the use of restraint.

In applying restraint, attempts should be made to explain to the adult what is happening, why, how long the measure is likely to last and who will be available during the period of restraint.

The risk of injury resulting from the use of restraint should always be borne in mind. Consequently, there should always be at least one member of staff/carer present (in visual and verbal contact) for as long as the adult is subjected to the measure of restraint. This may necessitate measures to ensure that there are sufficient members of staff available, particularly at night.

Any person who is involved in the application of measures of restraint should have received training in non-restrictive methods of care as well as in the use of restraint. Unless unavoidable or impractical, a male member of staff should not be employed to restrain a female.

Mechanical restraint

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

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

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

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

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

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

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

**Physical restraint**

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

Staff and carers should be trained in how to physically handle adults in this way, as incorrect use of this means of restraint could cause injury. It could also be interpreted as an attack and provoke a reaction of fear, perhaps further exacerbating the situation.

**Locking doors**

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

**The locking of doors other than in the context of placement**

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

**Tagging**

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

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

**Video surveillance**

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

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

Ordinarily, there should be no justification whatsoever for the use of video surveillance in private living areas such as bedrooms, bathrooms and toilets. In exceptional circumstances (i.e. where its use is considered to be the least intrusive measure available), video surveillance should be permitted in private living areas solely with the consent of the adult with incapacity (if s/he is able to give it) or failing this of the guardian and/or close relatives. In such cases, the reasons for such surveillance should be considered and stated within a care plan, it should be for a time-limited period and the decision should be reviewed on a regular basis (preferably daily).

**Passive alarms**

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

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

**Medication as restraint**

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

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

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

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

Psychological restraint

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

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

Staff and carers should be made aware of the need to respect the rights and dignity of the adult at all times. They should also bear in mind how the adult might perceive their behaviour towards him/her, particularly in view of the potential unequal distribution of power and the adult's possible perception of this.
2.5 Annex 2: Minutes of meetings

2.5.1 Steering Committee Meeting of 9 March 2010 in Brussels

Present
Jean Georges (JG)
Cornelia Reitberger (CR)
François Blanchard (FB)
Michael Schmieder (MS)
Alain Franco (AF)
Celso Pontes (CS)
Dianne Gove (DG)
Bénédicte Gombault (BG)
Magda Aelvoet (MA)
Iva Holmerová (IH)
Annette Dumas (AD)

Apologies
Sigurd Sparr (SS)
Matthias von Schwanenflügel (MvS)
Cees Hertogh (CH)
Sabine Jansen (SJ)

2.5.1.1 Introduction

JG opened the meeting, welcomed participants and passed on apologies from SS, MvS and CH. He extended a special welcome to MA and BG from the King Baudouin Foundation in Belgium and invited them to talk about their preparations for the Joint Action Plan later in the meeting. He then distributed a document (Dementia Ethics Network, draft 7 of 15 February 2010) and explained the origin and objectives of the project, highlighting the fact that the whole project stemmed from the original idea of MS. He pointed out that it was not possible to deal with all ethical issues related to dementia at once and that consequently, it had been decided to focus on assistive technology (AT) and research involving people with dementia this year, with a publication containing a literature review and guidelines on the ethical issues linked to using AT with people with dementia being published by the end of the year (in the same format as our past publications on end-of-life care and advance directives).

IH thanked MS for having shared his idea at European level, the German Ministry of Health for having started this important project and the Belgian presidency for its interest in supporting this topic as it was very important that AD was considered a European issue.

2.5.1.2 Financial and organisational issues

JG provided details about the funding of the project. The German Ministry of Health originally provided financial support to the German Alzheimer Association which in turn provided Alzheimer Europe with the financial support for this project. This year, support for the project was provided by the European Commission through the operational grant which covers AE’s core activities. This funding therefore has to cover other activities such as the work on legal issues and the organisation of the 20th European conference in Luxembourg.

2.5.1.3 Discussion about hierarchies of ethical principles

FB and AF arrived, introduced themselves and gave some feedback about the written document that had been prepared. FB felt strongly that autonomy should not be presented as the most important ethical principle and felt that the ethical principles should be presented in the following order:

1. Humanity/dignity
2. Solidarity
3. Equity/justice
4. “Bien traitance” (Beneficence/non maleficence)
5. Autonomy

DG explained that there had not been any intention to present the ethical principles in the form of a hierarchy but FB felt that a hierarchy was nevertheless implied and that in his opinion, it should be as above. AF offered to provide DG with a power point presentation he had made covering a wider range of ethical principles which she could use as a source of additional information for that section on the website (e.g. to add details about other ethical principles). A discussion ensued which the participants came back to at several points during the meeting about whether there should be a hierarchy and if so, where autonomy should be placed in that hierarchy. Opinions were divided and included the following:

- In other countries, there is a different hierarchy (e.g. in Mexico, justice is at the top)
- Different cultures attribute different meanings to the various principles.
- Autonomy is always important but makes no sense in the absence of other principles such as dignity and equity.
- Autonomy make take on a special importance in the case of dementia as that is the very thing that is threatened.
- People who have autonomy value it highly and may find it disturbing to witness its loss (based on mental capacity) or failure to promote/respect it (as an ethical principle) with regard to other people (who may themselves place a higher value on other ethical principles).
- People tend to have difficulty dealing with shifting hierarchies.
- Some ethical principles are not more important than others as what is important depends on a range of factors such as the situation, the person or people concerned and the severity of the disease. One must be attentive to the lived experience of the people concerned for whom different ethical principles may be important.
- Certain non-Western societies, which place much less emphasis on autonomy in their lives in general, have less difficulty dealing with issues linked to loss of autonomy.

2.5.1.4 Ethics section of the AE Internet and publication on AT

DG gave an overview of some of the main points raised in the working group meeting on assistive technology which took place the day before. She then described the main changes/additions to the document containing all the information on the Internet on ethical issues. The main additions included: a longer introduction outlining what ethics is and isn’t, and sections on solidarity/interdependence (following FB’s previous comments), dignity and personhood.

MS commented that he liked the information on the website and appreciated the fact that it was presented in a neutral manner. IH also felt that the information was good and thorough but offered to pass on the sections addressing philosophical issues to an expert she knew in philosophy in order to check them and make any necessary amendments. In response to DG’s question about possibly including sections on liberty, respect and privacy, she felt that this was already covered in the section on dignity and was therefore not necessary.

JG pointed out that as euthanasia is illegal in most European countries AE did not think it appropriate to cover this issue. He asked whether the group agreed to the text with proposed amendments being put on the Internet. There were no objections to this. He added that if anyone had any comments about any part of the text to simply forward them to DG.

MA and BG both proposed to send documents (a power point presentation by Nathalie Rigaud on ethical principles and a text from the University of Ghent on AT).

2.5.1.5 The discussion forum and other uses of the ethics section

JG explained how the discussion forum would work and gave a practical demonstration of this function on the ethics section of the AE website. It was agreed that the information from the discussions could contribute towards the development of cases/vignettes which could be presented along with discussions of the ethical issues involved and guidelines on dealing with such situations. People using the forum will have to login but will have the opportunity to post anonymously. The discussion forum will be monitored but we will have to see how it develops as it is as yet unclear how much staff time this will take up.
AF stressed the importance of not presenting ethics as an anti-technology or of painting an overly negative picture of AT and emphasised the need to demystify ethical issues and teach people how to behave in an ethical manner and respect people with dementia. He felt that the main problems were not linked to ethical principles but rather to providing good practice. The group agreed that a space was needed to present good practice. JG agreed stating that we do not want to hinder the use of AT but rather to provide an ethical framework for its use.

IH suggested including links and JG explained that a list of key documents would also be available.

2.5.1.6 Administrative matters

As the funding from the German Ministry of Health runs out at the end of March, JG asked everyone to send invoices for reimbursement to him as quickly as possible.

2.5.1.7 Members of various group linked to the Dementia Ethics Network

JG asked for assistance contacting Carlo Defanti and Andreas Kruse or to propose other people instead for the steering committee. IH suggested contacting Catalina Tudose.

For members of the national ethics correspondents group, JG asked for suggestions. BG suggested Herman Nys and Nathalie Rigaud. JG suggested contacting Ruud Ter Meulen and explained that the members of the working group on AT would all be members of this group.

For the working group on dementia research, we only have one member so again, proposals would be welcome.

The advisory group will consist of representatives from ministries and foundations such as the German Ministry of Health, the Luxembourg Ministry of Family, the King Baudouin Foundation and perhaps the Fondation Médéric Alzheimer amongst others.

2.5.1.8 Future funding for the continuation of the Dementia Ethics Network

The importance of obtaining financial support for the network from several foundations was discussed. JG stated that ideally AE should have core funding for its activities as well as specific funding for this network but that so far, nothing concrete had been proposed.

To create a safety net, Foundations like the King Baudouin Foundation or Fondation Médéric Alzheimer should be approached to provide funding for the project.

MA described the recent difficulties experienced by the King Baudouin Foundation in connection with the application they would like to make within the framework of the Joint Action Plan on Alzheimer’s disease to be supported by the European health programme and coordinated by the French Ministry of Health (through the Haute Autorité de Santé) with 50% of the funding coming from the European Commission (Public Health Framework Programme) and 50% from the Member States.

However, some points have since emerged which are unclear/uncertain:

- While the European Commission mentioned EUR 1 million for the project, the amount stated in the documents received by the participating countries mentioned EUR 500,000.
- The assignments of work packages to work package leaders have not been confirmed yet and France is finding it difficult to find collaborating partners.
- While it was originally decided that the project would have 7 work packages, including a specific work package that would be led by Belgium (the King Baudouin Foundation) on the rights of people, their autonomy and ethics in general, it now appears that there will only be 6 work packages, with ethics being diluted among other topics in a work package. Belgium having been offered the leadership of this melting pot work package.

MA stressed the interest of Belgium to coordinate work on certain ethical/legal issues about the issues of competence and competence assessment whereas France seems to have a preference for a wider care-related work package in which these issues would be included.

It was agreed that the King Baudouin Foundation should make direct contact with the person responsible for handling the application (Professor Bacou from the Haute Autorité de Santé) in order to clarify the situation. The deadline for submitting the proposal to the European Commission is 19 March 2010.
JG explained that AE would apply for an operational grant under the health programme and that the continuation of the dementia ethics network would be an important part of this application. He expressed his concerns that the European Commission may consider supporting the Joint Action as sufficient funding for the field of Alzheimer’s disease and that the AE application may therefore have less chance of success. Nevertheless, he added that if we have political backing from various ministries, there should be no conflict between the Joint Action and AE’s ongoing funding but that the Commission must receive a clear signal that joint action and operational support are both necessary.

At the same time, CR suggested contacting foundations to support the AE activities and MA suggested establishing a funding plan for the attention of possible foundations.

2.5.1.9 Close of the meeting and future dates

JG thanked everyone for their participation and brought the meeting to a close. CR invited all present to a conference being held in Berlin on 21 September 2010 and explained that official invitations would be sent out. Everyone thanked her for the invitation and JG said that he would love to attend but some of the members of the group already realised that they would probably be unable to attend due to commitments at national level linked to World Alzheimer’s Day. If a sufficient number of people do eventually attend, JG suggested holding the next steering committee meeting on the following day (i.e. 22/09/2010 in Berlin).
2.5.2 “Assistive Technologies” Working Group Meeting of 8 March 2010 in Brussels

Present
Alistair Niemeijer (AN)
Annette Dumas (AD)
Dianne Gove (DG)
Heike von Lützau Hohlbein (HLH)
Inger Hagen (IH)
James McKillop (JMK)
Jean Georges (JG)
Luiza Spiru (LS)
Maria McManus (MMM)
Maureen McKillop (MMK)
Sirkkaliisa Heimonen (SH)
Stefania Kapronczay (SK)

Apologies
Cees Hertogh (CH)

2.5.2.1 Introduction

DG opened the meeting and welcomed participants. JG passed on apologies from CH. DG then provided an overview of the document she had prepared on assistive technology (AT) and asked for any comments.

JG provided background information about how the project had come about, what its goals were and how the work on AT fitted into the overall project.

2.5.2.2 Morning presentations on the perspectives of people with dementia, informal carers and professional carers regarding the ethical use of AT

JMK, HLH and SH gave talks on the perspective of people with dementia, informal carers and professional carers regarding AT. JMK spoke about capacity, consent and difficulties some people with dementia have using AT. He also drew attention to the need to avoid the use of certain terms to refer to people with dementia such as “suffering from dementia” and “demented”, showed a piece of AT that he uses, asked whether other people had noticed it and said how he personally felt about using it. He regularly intervened during the meeting to share his perspective and experience of someone living with dementia and a potential AT user. HLH stressed the golden rule that AT should always be a form of help and never to replace care. She pointed out that carers are often unclear about the legal aspects of using AT, may consider that the practical and ethical issues linked to its use differ depending on when and by whom it is used, and that it is necessary to look at the real life situations that people find themselves in when faced with ethical dilemmas linked to its use. SH looked at the values, aims, process and ethical dilemmas linked to the use of AT by professional carers. She emphasized the importance of evaluating functional capacity and identifying remaining abilities and skills, as well as motivation and willingness to use AT, and obtaining a holistic understanding and comprehensive information on the situation of the potential AT user, including a good knowledge of dementia, so as to help plan individually tailored applications. The presentations were followed by a discussion in which the following issues were raised.

- There are other ethical issues to be considered. IH mentioned a review of ethical principles drafted by the ICT and Ageing in the context of a project financed by the European Commission.
- Sometimes respecting the autonomy of the person with dementia may jeopardize the safety or wellbeing of other people.
- AT should be used primarily for people with dementia but if it can also be beneficial for informal and professional carers (e.g. to help prevent the onset of depression or burnout), then all the better.
In Norway, there is a legal right to AT but a lack of awareness amongst all shareholders.

AT is not generally mass produced and therefore tends to be expensive.

People do not necessarily want to go to the kinds of shops where AT is sold and it is not marketed in a very positive way (i.e. it is not marketed as something that is cool and trendy or a “must have” like the latest iPod).

AT for people with intellectual disabilities seems to be marketed in a more positive way and parents seem to be willing to invest in it.

We need to look at how AT is being used in other patient groups and see whether it might be useful for people with dementia.

Professional carers often lack knowledge. They need to be educated about the problems faced by people with dementia and see the whole picture rather than looking for hasty solutions.

An ethical framework for decision making is needed, particularly as AT development is a fast moving, creative but volatile area.

This should take into account the provisions of the Convention on Human Rights.

There is a need to raise awareness of the ethical issues surrounding the use of AT at home.

It is important to focus on a psycho-social model of dementia (which is the case in the literature review).

Some people with dementia are also carers themselves (e.g. grandparents who are bringing up their grandchildren due to divorce within the family etc.). They may need a lot of assistance, including AT.

2.5.2.3 Afternoon presentations and discussion on the ethical use of AT

On the topic of legal issues, SK considered the issue of guardianship and how in many cases, decisions about AT involve the family but the views of the person with dementia should also be taken into account. She explained about supportive decision making in Hungary and the importance of obtaining assent from people with dementia who lack the capacity to consent, even though this has less legal value. Supported decision making means that without diminishing one’s legal capacity he/she has a supporting person who officially helps him/her in making decisions. The supporting person has the right to be present and be informed. Another important thing is the advanced directive – with which a person with dementia can decide in advance what kind of treatment he/she accepts or does not accept.

She drew attention to the relevance of data protection laws for the use of certain forms of AT (e.g. computerized or video surveillance and monitoring) and highlighted the close link between ethical and legal issues. She also drew attention to the issue of discrimination regarding access to AT. For example, if dementia is not officially recognised as a disability in a particular country, will people with dementia have access to it? The group agreed that it would be worthwhile looking into whether dementia is legally considered as a disability in each country and finding out about data protection laws in each country and also to the data protection directive of the European Union which applies to each member state.

LS described the social and cultural factors in Romania such as it having 18 minority groups and having the lowest state expenditure on health in the EU. She looked at the cultural, social and legal constraints to the use of AT and the possible resulting ethical conflicts (e.g. level of education and computer literacy and the need to avoid damaging self-esteem; customs and religion and the need to respect privacy and beliefs; geographical area and type of residence and the need to ensure equity of involvement and dialogue with users and representatives; and finally uncertainty about rights and responsibilities and the need to improve guidelines and laws). She also considered how cultural barriers such as language barriers and religious dogma might interfere with the consent process for research.

This was followed by a presentation by AN who considered how AT could positively contribute towards the respect of ethical principles. He highlighted the absence of a clear normative framework and little attention being paid to the use of technology in dementia care (particularly in the home environment). He covered three main issues: duty of care vs autonomy; freedom and consent; and dignity/stigma, and concluded that there is a lack of RCT research, no ethical consensus underlining the need for clearer policies, many articles on AT lack indepth analysis of ethical principles such as dignity and there are differences in attitudes towards the use of AT between the US and the UK. He suggested investigating
different ways of looking at ethical principles and issues such as Agich’s concept of actual autonomy or Nussbaum’s dignity based on remaining capabilities.

The issue of whether AT was neutral was discussed (i.e. does it just depend on the way that it is used?) and there was a gradual movement towards acceptance that it is not as value-judgements are made even in the development phase. MMM highlighted certain cultural factors which may lead to an abuse of AT. For example, in rural Ireland where property is highly valued, people may use all available means to keep a person at home as going into residential care could in certain cases lead to the loss of property (to finance the care) or using up their future inheritance. Consequently, AT may be used in the wrong way (e.g. extensive use of video surveillance with failure to respect privacy or consider consent). This results in a kind of cultural ambivalence about the relevant practical and ethical issues. MMM concluded that we have to address the way it is used in the real world and not stick to theoretical debates if we are to ensure that it is used ethically and in a way that is beneficial to people with dementia.

The use of AT in residential care/nursing homes was discussed. HLH drew attention to the conflict between ethical ideals (e.g. AT not replacing staff) and the situation in the real world (i.e. no new staff will be taken on in any case as no one is willing to pay for them). JG drew attention to the fact that rules governing the use of AT may be more comprehensive in nursing homes. AN added that discussions about the ethical use of AT often overlook the rights of health and social care professional (e.g. what about their right to privacy when video surveillance is installed). MMM suggested that as laws don’t adequately cover private homes, there is perhaps a need to scrutinize the provisions of the Convention on Human Rights and see how they could be applied to the home care environment (and the ethical use of AT).

JMK questioned why AT could not be specifically for carers. MMK expressed her view that as the disease progresses, it becomes increasingly important for carers to take over decision making and sometimes the decisions they make are not what the person with dementia wants but in his/her best interests.

### 2.5.2.4 Literature review

During the meeting, members of the working provided DG with some of the documents that she had been unable to access for the literature review. Some promised to forward others and some had sent several documents prior to the meeting which DG would find on her return. AN offered to help with access to further documents if need be.

### 2.5.2.5 Deliverables

The group concluded that it was not sufficient to simply highlight the ethical issues involved but that in addition the working group should develop an ethical framework for decision making including guidelines which could be used by individuals faced with ethical dilemmas but also by professional bodies and even governments interested in developing their own guidelines. Such guidelines should nevertheless be sufficiently flexible to be applied to a range of very different dilemmas involving different people in different environments.

### 2.5.2.6 Close of the meeting

DG brought the meeting to a close and thanked participants for their valuable contribution.
2.5.3 Steering Committee Meeting and “Assistive Technologies” Working Group Meeting on 22 September 2010 in Berlin

Present


Apologies


2.5.3.1 Introduction

MVS opened the meeting, welcomed participants and proposed a round table so that participants could introduce themselves to the others present. This was helpful as this was a joint meeting of the steering committee and the working group on assistive technology. As MVS unfortunately had to leave early, it was agreed to amend the agenda in order to deal with issues linked to the steering committee first and then to spend the rest of the day working on the assistive technology (AT) document. Participants from both groups took part in both parts of the meeting.

2.5.3.2 Steering committee discussions

MVS asked where Alzheimer Europe (AE) was with the financing of the continuation of the project. DG explained that she was not involved in funding issues at all but that according to JG AE has applied to the EC for funding for the activities of the organization, including work on the EDEN and although AE is first on the reserve list, we have not yet received any funds and must simply wait for the time being. JG had also mentioned that regardless of whether we receive this funding, work on ethical issues has been included in our next work plan. Consequently, whatever happens we hope to be able to continue this important work in some way. MVS then asked about funding from the foundations but DG was not aware of the status with regard to this. MVS wondered whether lobbying might help and it was agreed that it possibly would and that JG could let us know if this was the case.

MVS felt that we should not rely on EC funding and informed the group that he had already spoken to someone from the Robert Bosch Stiftung regarding possible funding although nothing has so far come of this. SS asked if the German Health Ministry was able to provide any funding to which MVS replied that it unfortunately was not in a position to do so.

The idea of dividing up the project into sub-projects for the purposes of funding was put forward by SJ and BG. The latter pointed out that foundations generally want something concrete to fund (e.g. a workshop) and do not tend to provide structural funding.
CB asked what had become of the original idea about the Internet platform. DG explained that JG had been working on this. CB felt that it was necessary to define steps and the process and that an organigramme would be very useful. He suggested that JG could perhaps do this, present it to the steering committee and then use it when approaching the foundations for funding.

SS summarised and highlighted three steps: 1. agree on the assistive technology, have it approved by the steering committee and publish it 2. set up the Internet platform 3. steering committee to decide on the next issues to pursue.

MVS was enthusiastic about the possibility of an Internet discussion resulting in debate across Europe which he described as added value. CB added that the paper on AT had value in itself but also for the platform where the dated could be widened.

AN drew attention to the possible difficulty getting carers involved as in his experience, they are often reluctant to get involved. He added that the platform would have to be really accessible and well publicised. PT felt that there could be a similar difficulty involving people in non-English speaking countries and that funding would be needed at national level for this. CB responded that this was why it was important to involve experts who would bring the discussion to European level and that this would avoid everyone just blogging with no streamlining. He also added that it was necessary to build up a structure and to consider how to do that.

MVS described the structure as follows:

1. National correspondents in each country
2. Steering committee
3. Advisory (working) group

MM asked if anyone knew of a similar kind of Internet platform which was considered as good practice. It was agreed that there is not really anything of this sort yet but that although slightly different in its objectives, a certain Kuratorium website funded by the German government was worth looking at.

MVS summarized the next three steps as being:

1. To contact foundations for funding
2. To work on the structure (organigramme)
3. To work on how to get the Internet platform fully operational

It was agreed that members of the steering committee should meet in November on the occasion of the Belgian Presidency Conference (25-25 November 2010), at which members of the European Commission would also be present.

Before closing this part of the meeting, BG was invited to talk briefly about the Joint Action Programme. She explained that Belgium would be coordinating the 7th work package on ethics covering advance declarations of will and competency assessments, along with the dissemination of information. This work will be carried out in collaboration with Finland (Pävi Topo) and France (François Blanchard).

She stressed that the involvement of AE and other associations was needed and that it was very important to make a link between this work and that of the dementia ethics network, particularly as the first objective is to promote collaboration.

CB stated that the German Health Ministry supported this and also thought that it was important to make a link between both projects and determine what the respective structures would be like.

MVS then ended this part of the meeting, wished participants a productive meeting and left.

2.5.3.3 Discussion about the finalization of the report on AT

The rest of the day was taken up discussing the document on the ethical issues linked to the use of AT by/for people with dementia. SS kindly agreed to chair the meeting. The group systematically went through every section of the report (starting with section 5 and working backwards). For each section, DG presented the comments made by members of the working group who had been unable to attend but had sent their comments earlier by email. This included comments by SH, CH and IHG. Practically all of these comments were accepted and will be incorporated into the text as suggested or in a couple of cases, a compromise was found.
A couple of comments, including some by JMK, were not discussed but simply accepted as they
concerning typing or grammar, or in some cases points to add which in the course of the discussions
had already been brought up by some of the participants present.

The group was very active and contributed greatly to the improvement of the document. On certain
issues there were differences of opinion but the group managed to agree on the changes to be made.
These will not be highlighted individually here but will be visible in the next draft of the text which will be
sent to the steering committee for approval.

- AN agreed to write a few paragraphs on ethical theories, provide some information on 4 types
  of dignity as well as details of Nussbaum’s list of capacities, to check whether he has
  anything on the tendency of people with dementia to acquiesce and lent DG a book which
  includes some extra information that could be included.
- Mary Marshall agreed to look for a couple of vignettes.
- Michael Schmieder agreed to write a short vignette about how they approach ethical decision
  making at his centre.
- Stefania Kapronczay agreed to check whether the European data protection law covers live
  or stored visual recordings so that we can something more definite about this in the report
- Bénédicte agreed to find the contact details of an expert in socially assistive robotics who
  could be contacted to see if anything could be added to the section on that topic.
- Luiza Spiru agreed to send details of documents to include in the references section.

The document will be slightly restructured (e.g. section 4.1 to be expanded and become part 6; section
4.2. to be included as an annex) and in a couple of places, there will be clearer “bridging” between the
sections. It was also considered important to explain at the beginning of the guidelines (currently
section 5) for whom they are intended.

There is a tight deadline for this of a couple of weeks as we need to have a final draft ready by the third
week in October to be sent to the steering committee so as to have a final version for the printers by the
end of October. This would mean that we could publish the document at the end of this year.

It was suggested that it would be beneficial to produce easy-to-read summaries for different groups of
people. DG felt that this was a good idea but that it was not feasible in view of the time limit to include it
in the current publication (but that this could perhaps be done later). JMK stated that in his opinion the
document was already highly readable (e.g. he could understand 98% and the few parts that he did find
somewhat difficult tended to be the quotes from researchers).

Having covered all the sections, SS brought the meeting to a close and thanked the participants and for
their work and in the German Ministry, in addition, for their hospitality and help organizing the meeting.
SS was thanked in return for chairing the meeting.
3 Legal Rights Project

3.1 Aims

Based on its previous European Commission financed project Lawnet, Alzheimer Europe will update the national reports on the guardianship systems of the previously studied 15 Member States of the European Union and develop reports for those countries not previously studied (10 new Member States and Iceland, Norway, Switzerland and Turkey). These comparative reports will be published with the 2010 Dementia in Europe Yearbook of the organisation.

3.2 Achievements and results

In 1998, Alzheimer Europe had dedicated a project to an inventory of legislation affecting people with dementia. The successful Lawnet project resulted in the development of national reports for the 15 Member States of the European Union.

In 2009, Alzheimer Europe decided to embark on a three year project to update the national reports to include all legislative reforms which had been undertaken since the earlier Lawnet project and to develop national reports for those countries that had joined the European Union, as well as other countries covered by the organisation (Iceland, Norway, Switzerland and Turkey).

As a start, the organisation focused on biomedical issues (including consent to treatment, the right to information, advance directives and end-of-life questions) in 2009. In 2010, Alzheimer Europe developed national reports on the issues of proxy decision making (e.g. guardianship measures and continuing powers of attorney) and various forms of legal capacity (e.g. relating to marriage, making a will or a contract, voting, civil liability and criminal responsibility).

Alzheimer Europe was able to count on the active contributions of several legal experts from its member organisations, as well as a number of independent lawyers and legal experts. In addition, Alzheimer Europe received the support of Fondation Médéric Alzheimer for the development of the 29 national reports which were published in the 2010 edition of the organisation’s Dementia in Europe Yearbook.

3.3 Deliverables

The project resulted in the following deliverables:

- National reports on legal capacity and proxy decision making in dementia

Thanks to the support of national Alzheimer associations and legal experts, it was possible to conclude the national reports for the countries of the European Union (with the exception of Cyprus and Slovakia) as well as Iceland, Norway, Switzerland and Turkey. For the United Kingdom, separate reports were produced for England and Scotland due to the differences in legal systems.

These reports covered the national systems by which people can lose legal capacity, as well as the systems for the appointment of a proxy to make decisions on behalf of someone no longer able to make these decisions him/herself.

In addition, the reports how legal systems dealt with capacity in different areas, such as:

- Marriage and divorce
- Voting capacity
- Testamentary capacity
- Contractual capacity
- Civil liability
- Criminal responsibility.

The national reports were included in the 2010 version of the Dementia in Europe Yearbook. Copies of the yearbook are annexed to this report.
4 Involving people with dementia

4.1 Aims

Alzheimer Europe will carry out a survey of its member organisations on how people with dementia are involved in national Alzheimer associations and their activities, as well as in policy developments on a national level and develop recommendations on how best to promote the active involvement of people with dementia.

4.2 Achievements and results

Alzheimer Europe carried out a survey of its member organisations in which it enquired about how best to involve people with dementia in future activities. Three key recommendations of the Alzheimer Europe Board (the involvement of people with dementia in project working groups, the inclusion of people with dementia as speakers at conferences and the setting up of a bursary system for people with dementia for AE conferences) all received the overwhelming support of the members of Alzheimer Europe and will be formalised in the framework of a forthcoming review of the organisation’s statutes.

However, Alzheimer Europe did not await the conclusions of the survey to fully involve people with dementia in its activities. James McKillop participated in the working group on assistive technologies set up in the framework of the Dementia Ethics Network and was invited as a keynote speaker at the organisation’s Annual Conference in Luxembourg. In order to encourage the participation of people with dementia in AE activities further, a bursary system was created which covered the costs for people with dementia from different European countries to attend the conference. In addition, a section of the organisation’s Dementia in Europe Magazine was dedicated to presenting personal accounts by people with dementia and their carers.

The survey of members also proposed different models for involving people with dementia in the decision making process of the organisation and a majority of members expressed their support for the establishment of a European Advisory Group of people with dementia who would elect a person with dementia to the Board of Alzheimer Europe.

4.3 Deliverables

The project resulted in the following deliverable:

- **Recommendations on the involvement of people with dementia**

The recommendations take into account the findings of the membership survey carried out by Alzheimer Europe and provide guidelines on the involvement of people with dementia in the organisation’s projects, meetings and governance.
4.4 Annex: Recommendations on the involvement of people with dementia

4.4.1 Introduction

Alzheimer Europe has been successful in involving people with dementia in its activities. In the past, Alzheimer Europe has done so on an ad hoc basis by:

- Inviting people with dementia to participate in working groups (advance directives, end-of-life care, assistive technologies) as experts,
- Asking people with dementia as keynote speakers and participants in plenary sessions at all Alzheimer Europe conferences since 2005,
- Creating a bursary system and covering the travel and accommodation expenditure for people with dementia to the Alzheimer Europe conferences in Brussels and Luxembourg.

However, the Scottish Working Group on Dementia wrote to Alzheimer Europe expressing their concern as to the low number of people with dementia participating in or attending Alzheimer Europe conferences. Also, at previous Annual General Meetings, some people with dementia raised the issue of the involvement of people with dementia in the governance of Alzheimer Europe.

Despite a number of discussions within the Alzheimer Europe Board on the subject, no formal proposals have been made on how to improve the involvement of people with dementia.

The question of involving people with dementia also formed a part of the membership survey which Alzheimer Europe carried out in 2010 and member organisations were generally supportive of the ways in which Alzheimer Europe had involved people with dementia so far:

- 91.3% of members agreed (52.17% strongly agreed) with the suggestion of involving people with dementia in plenary sessions,
- 91.3% agreed (43.48% strongly agreed) with the suggestion of creating a bursary system for people with dementia to attend AE Conferences,
- 65.2% agreed (26.09 strongly agreed) with the suggestion of involving people with dementia in working groups.

Asked on how best to involve people with dementia in the governance of Alzheimer Europe, a majority of members (57%) opted for a system where a person with dementia was elected to the Board by a working group of people with dementia. 22% of members supported a system whereby the AE Board could co-opt a person with dementia, 13% for a system where one seat on the AE Board would be reserved for a person with dementia and 9% of members would have left the current system unchanged where national organisations can put forward a person with dementia as their candidate to the AE Board.

Based on these discussions, it is therefore suggested that the Board adopt actions on the basis of the suggestions outlined below.

4.4.2 Suggestions for improving the involvement of people with dementia

4.4.2.1 Involving people with dementia in Alzheimer Europe conferences

It is important to ensure that people with dementia are able to participate in the conferences of Alzheimer Europe as highlighted by the Scottish Dementia Working Group.

It is therefore suggested that in future:

<table>
<thead>
<tr>
<th>Suggestion</th>
<th>How</th>
</tr>
</thead>
<tbody>
<tr>
<td>A person with dementia from the host country shall be asked to participate</td>
<td>New article (6.5.1.) to be added to conference guidelines – to be</td>
</tr>
<tr>
<td>in the opening ceremony of future Alzheimer conferences. Should this</td>
<td>adopted by AE Board</td>
</tr>
<tr>
<td>not be possible, Alzheimer Europe will suggest a person with dementia</td>
<td></td>
</tr>
</tbody>
</table>
from another country to do so.

A workshop will be organised at each conference solely dedicated to an exchange of information and experiences between people with dementia.

New article (6.5.2.3.) to be added to conference guidelines – to be adopted by AE Board

A special room will be set aside for people with dementia to allow them to withdraw from the busy conference and to exchange views with other people with dementia in an informal fashion.

New article (8.6) to be added to conference guidelines – to be adopted by AE Board

Involving people with dementia will feature as a subject in every call for abstracts for AE conferences.

New article (5.3.3.) to be added to conference guidelines – to be adopted by AE Board

Alzheimer Europe will waive the registration fees of up to ten people with dementia who can be accompanied by their carer whose registration fee will also be waived. AE’s member organisations will be asked to suggest candidates. The places will be allocated on a first come, first served basis. No member organisation will be represented by more than one person and his/her carer.

New article (10.3) to be added to conference guidelines – to be adopted by AE Board

4.4.2.2 Involving people with dementia in AE activities and projects

In addition to the involvement of people with dementia in AE Conferences, Alzheimer Europe will ensure that people with dementia are able to contribute to the organisation’s activities and projects.

Alzheimer Europe will establish a European Working Group of People with Dementia. The designation of members and terms of reference of this working group will be determined in AE’s rules and regulations.

Alzheimer Europe will ensure to have at least one person with dementia in any working group set up by the organisation. The person with dementia will be nominated by the European Working Group of People with Dementia.

4.4.2.3 Involving people with dementia in the governance of the organisations

Alzheimer Europe will therefore reserve one position on the Alzheimer Europe Board for a representative of the European Working Group of People with Dementia.

The members of the European Working Group of People with Dementia will elect a Chairperson who will sit on the Alzheimer Europe Board with full voting rights. Alzheimer Europe will cover the travel and accommodation expenses for the attendance at Board meetings of this representative and his/her carer, if necessary.

This change of the composition of the AE Board will require a statutory reform and the election of the representative of the European Working Group of People with Dementia to the Board will need to be determined in the organisation’s rules and regulations.

4.4.3 Proposed changes to the AE Statutes and AE Rules and Regulations

4.4.3.1 Statutory Changes

<table>
<thead>
<tr>
<th>Old Article</th>
<th>New Article</th>
</tr>
</thead>
<tbody>
<tr>
<td>Title VI: Board of directors</td>
<td>Title VI: Board of directors</td>
</tr>
</tbody>
</table>
### Article 20 – Composition

The Board of Directors shall be comprised of the office bearers, as well as between three and eight further members directly elected by a General Meeting.

All directors must be members of full member organisations of Alzheimer Europe.

### Article 29 – Proxies and quorum

The Board may make valid decisions if half of its members are present or represented.

Directors may be represented at meetings by any other Director who must be the bearer of a written proxy.

The Chairperson is the sole judge of the validity of a proxy and his (or her) decision shall be final and binding.

The decision of the Board shall be made by a simple majority of the votes of those present or represented. In the case of a tied vote, the Chairperson shall have a casting vote.

### New Article 35 – European Working Group of People with Dementia

Alzheimer Europe will set up a European Working Group of People with Dementia comprised of people with dementia nominated by the member organisations of Alzheimer Europe. The composition and terms of reference of this Working Group will be determined in the Rules and Regulations of the organisation.

#### 4.4.3.2 Changes in Rules and Regulations

In order to determine the composition and terms of reference of the European Work Group of People with Dementia, it is suggested to include the following new articles to the organisation’s rules and regulations:

**XV. European Working Group of People with Dementia**

**Article 41 – Aims**

In recognition of the unique contributions people with dementia can provide with regard to their experience of dementia, Alzheimer Europe will set up a European Working Group of People with Dementia.

The Working Group will be asked to advise the organisation in the development of positions and policies and ensure the organisation adequately represents the interests of people with dementia as well as carers.

**Article 42 – Working methods and meetings**

The working group shall meet once a year in the framework of the Alzheimer Europe Conference. A meeting room will be set aside for this meeting. Alzheimer Europe will cover the travel and accommodation expenses for up to ten people with dementia to attend the meeting. Member organisations are encouraged to support additional people with dementia to attend AE Conferences.

In between meetings, communication will be done by e-mail and if requested, Alzheimer Europe can organise a telephone conference for participants.

All communication will be in English. However, member organisations of Alzheimer Europe are strongly encouraged to provide support to people with dementia to actively engage in the activities of the Working Group.

A member of the Alzheimer Europe staff will provide administrative and secretarial support when needed.

**Article 43 – Composition and mandate**

Each member organisation of Alzheimer Europe may nominate a person with dementia to the European Working Group of People with Dementia. If organisations are unable to nominate a person with dementia to the Working Group, their places can be taken up by other people with dementia nominated from other member organisations. However, no member organisation may have more than three people with dementia on the European Working Group.

The Alzheimer Europe Secretariat will ask for nominations two months in advance of the organisation’s Annual General Meeting. The mandate for members of the Working Group is for one year and can be renewed.
Article 44 – Chairperson and Vice-Chairperson

The members of the Working Group will elect a Chairperson and Vice-Chairperson from amongst their members. The election will take place at the meeting of the Working Group at the Alzheimer Europe Conference. The mandate of the Chairperson and Vice-Chairperson is for one year and can be renewed.

Meetings of the Working group will be chaired by the Chairperson and in his/her absence by the Vice-Chairperson.

As set out in the Statutes of Alzheimer Europe, the Chairperson of the European Working Group of People with Dementia will be an ex-officio member of the Alzheimer Europe Board. He/She can be represented by another member of the Working Group who must be the bearer of a written proxy.
5  European Dementia Observatory

5.1 Aims

Alzheimer Europe will continue to gather and disseminate all information on dementia at both a European and national level and will focus on policy developments, such as the implementation of the European Commission Alzheimer's initiative and national dementia strategies and plans, as well as scientific developments with regard to new treatments and new care approaches.

5.2 Achievements and results

In the past years, Alzheimer Europe has greatly improved the information it provides to its members and external stakeholders on key developments. As a long-term objective, Alzheimer Europe would like to set up a European Dementia Observatory where all relevant developments in the dementia field would be monitored and reported on.

In 2010, the monthly e-mail newsletters contained information on the latest activities of Alzheimer Europe and those of the European Alzheimer’s Alliance and its member organisations, as well as information on interesting policy initiatives both on a national and European level. Alzheimer Europe also covered research developments in its monthly newsletter.

A total of 474 articles were featured in 2010 in Alzheimer Europe’s monthly e-mail newsletters and these articles can be broken down as follows:

<table>
<thead>
<tr>
<th>Subject</th>
<th>Number of Articles</th>
</tr>
</thead>
<tbody>
<tr>
<td>Activities and projects of Alzheimer Europe</td>
<td>28</td>
</tr>
<tr>
<td>European policy developments in the field of dementia</td>
<td>54</td>
</tr>
<tr>
<td>National policy developments</td>
<td>27</td>
</tr>
<tr>
<td>Activities and projects of AE member organisations</td>
<td>93</td>
</tr>
<tr>
<td>Scientific developments</td>
<td>202</td>
</tr>
<tr>
<td>Dementia in Society</td>
<td>35</td>
</tr>
<tr>
<td>New resources and publications</td>
<td>35</td>
</tr>
</tbody>
</table>

The information was also included on the Alzheimer Europe website which continued to receive a significant number of visitors throughout the year.

<table>
<thead>
<tr>
<th>Month</th>
<th>Visitors</th>
</tr>
</thead>
<tbody>
<tr>
<td>January 2010</td>
<td>12,003</td>
</tr>
<tr>
<td>February 2010</td>
<td>12,723</td>
</tr>
<tr>
<td>March 2010</td>
<td>15,419</td>
</tr>
<tr>
<td>April 2010</td>
<td>13,071</td>
</tr>
<tr>
<td>May 2010</td>
<td>12,645</td>
</tr>
<tr>
<td>June 2010</td>
<td>12,757</td>
</tr>
<tr>
<td>July 2010</td>
<td>12,114</td>
</tr>
<tr>
<td>August 2010</td>
<td>12,623</td>
</tr>
<tr>
<td>September 2010</td>
<td>15,996</td>
</tr>
<tr>
<td>October 2010</td>
<td>16,364</td>
</tr>
<tr>
<td>November 2010</td>
<td>16,068</td>
</tr>
<tr>
<td>December 2010</td>
<td>12,459</td>
</tr>
<tr>
<td>Total</td>
<td>164,242</td>
</tr>
</tbody>
</table>
5.3 Deliverables

The Alzheimer Europe website (www.alzheimer-europe.org) and the monthly newsletters constituted the key deliverables of this project.

The e-mail newsletters are included as an annex to this report.
6 20th Alzheimer Europe Conference in Luxembourg

6.1 Aims

Under the theme “Facing dementia together”, Alzheimer Europe will focus on the importance of partnerships which are necessary to improve the quality of life of people with dementia and their carers and address the stigma attached to this disease. The conference will be held in Luxembourg and it is hoped to attract 400 participants to the conference in line with the participation of previous conferences.

6.2 Achievements and results

In 2010, Alzheimer Europe celebrated its 20th anniversary and therefore chose to organise its Annual Conference in Luxembourg, where the organisation’s secretariat has been established since 1996.

Under the theme “Facing dementia together”, Alzheimer Europe and Association Luxembourg Alzheimer focused on the importance of partnerships which are necessary to improve the quality of life of people with dementia and their carers.

The conference was held under the Patronage of H.R.H. the Grand Duchess of Luxembourg and a number of high level national (Minister of Health Mars di Bartolomeo, Minister for Family and Integration Marie-Josée Jacobs, Minister for the Economy Jeannot Krecké) and European representatives (European Commission Director for Public Health Andrzej Rys) attended the conference.

Over 300 delegates from 34 countries attended the conference and listened to the keynote speakers who came from a variety of backgrounds and included:

- Philippe Amouyel (France)
- Dieter Ferring (Luxembourg)
- Dianne Gove (Alzheimer Europe)
- Iva Holmerová (Czech Republic)
- Julian Hughes (United Kingdom)
- Maria Isaac (European Medicines Agency)
- Christina Kuhn (Germany)
- Heike von Lützau-Hohlbein (Germany)
- Gráinne McGettrick (Ireland)
- James and Maureen McKillop (United Kingdom-Scotland)
- Antoni Montserrat (European Commission)
- Kaisu Pitkälä (Finland)
- Gerrit Rauws (Belgium)
- Bengt Winblad (Sweden)

A total of 97 presentations were made during the conference with parallel sessions being dedicated to a wide variety of subjects, such as:

- Assistive technologies and design
- Education and training
- Innovative care services and approaches
- International dimension of dementia
- National dementia strategies
- Non-pharmacological approaches
- Nursing home care
Alzheimer Europe asked participants to evaluate different aspects of the conference and a total of 57 delegates returned the evaluation forms. The different plenary sessions were all judged highly with between 68.75% and 84.09% of delegates rating the four plenary sessions as "good" or "very good" and only between 2.04% and 8.33% rating the plenary sessions as "poor". Similarly, 78.18% of delegates felt that the choice of topics for parallel sessions had been "good" or "very good". Of the various aspects of the conference, the time left for discussion amongst conference delegates was the only area rated as "poor" by 26.79% of delegates and Alzheimer Europe will ensure the possibilities for dialogue will be enhanced at future conferences. Asked whether delegates would recommend an Alzheimer Europe Conference to friends and colleagues, 90.57% replied positively and 9.43% negatively.

The Annual General Meeting of Alzheimer Europe also took place in the framework of the 20th Alzheimer Europe Conference in Luxembourg. At the meeting, the member organisations adopted the annual report and financial accounts and approved the work plan and budget for 2011. In addition, the members elected a new Board:

- Heike von Lützau-Hohlbein (Germany) as Chairperson
- Iva Holmerová (Czech Republic) as Vice-Chairperson
- Maria do Rosário Zincke dos Reis (Portugal) as Honorary Treasurer
- Sigurd Sparr (Norway) as Honorary Secretary
- Sabine Henry (Belgium), Liane Kadusch-Roth (Luxembourg), Patrick Maugard (France), Maurice O’Connell (Ireland), Sirpa Pietikäinen (Finland), Alicja Sadowska (Poland), Charles Scerri (Malta) and Henry Simmons (United Kingdom-Scotland) as members of the Board

### 6.3 Deliverables

The following deliverables were developed as part of the Alzheimer Europe conference in Luxembourg.

- The conference programme was printed and distributed to all conference participants.
- All accepted abstracts were also included on the conference section of the Alzheimer Europe website: [http://www.alzheimer-europe.org/index.php/EN/Conferences/Previous-conferences/2010-Luxembourg](http://www.alzheimer-europe.org/index.php/EN/Conferences/Previous-conferences/2010-Luxembourg)
- In addition, all plenary speakers were filmed and videos of their presentations were included in the conference section of the website. Also, the Powerpoint presentations of presenters were included on the website for those speakers who agreed to their presentation to be included.
6.4 Annex 1: Detailed conference programme

6.4.1 Thursday, 30 September 2010

18.00-19.00 (Red Room): Opening Ceremony
Opening comments and welcome by
- Liane Kadusch-Roth, Chairperson, Association Luxembourg Alzheimer
- Maurice O’Connell, Chairperson, Alzheimer Europe

Opening addresses by:
- Marie-Josée Jacobs, Minister for Family and Integration, Luxembourg
- Mars di Bartolomeo, Minister for Health, Luxembourg
- Andrzej Rys, Director of Public Health, European Commission

19.00-19.30 (Red Room): Keynote address
Jean Georges (Luxembourg): Celebrating 20 years of achievements – Alzheimer Europe

6.4.2 Friday, 1 October 2010

09.00-10.30 (Red Room) Symposium S1: Facing dementia together: People with dementia and their carers
Chairperson: Heike von Lützau-Hohlbein (Germany)
- S1.1. James and Maureen McKillop (United Kingdom): Facing dementia as a couple
- S1.2. Dieter Ferring (Luxembourg): Who will care for me? Trends in family caregiving in European countries
- S1.3. Gráinne McGettrick (Ireland): Slaying the dementia dragon: Alzheimer organisations responding to stigma and social isolation
- S1.4. Julian Hughes (United Kingdom): An ethical framework to support people with dementia and their carers

11.00-12.00 (Red Room) Parallel Session P1: Innovative Care services and approaches (1)
Chairperson: Carmen Sinner (Luxembourg)
- P1.1. Tracy Gilmour (United Kingdom): Post-diagnostic pilot project
- P1.2. Clive Evers (United Kingdom): Sight loss and dementia: developing effective services
- P1.3. Marissa Butler (Ireland): Developing palliative care in dementia services – An Irish action research project

11.00-12.00 (Blue Room) Parallel Session P2: Relationships, communication and sexuality
Chairperson: Sabine Henry (Belgium)
- P2.1. Razvan Ioan Trascu (Romania): Communicating with Alzheimer patients
- P2.2. Damian Murphy (United Kingdom): Attending to communication difficulties between people with dementia and family carers: A relationship-centred approach
- P2.3. Anja K. Leist (Luxembourg): Feelings of family caregivers towards the cared-for person with dementia – A micro-analytic approach
- P2.4. Magda Tsolaki (Greece): Sexual function in dementia and related issues

11.00-12.00 (Yellow Room) Parallel Session P3: Perceptions of dementia
Chairperson: Sirkkaliisa Heimonen (Finland)
- P3.1. Géraldine Viatour (France): Impact of practice changes of professional caregivers on their social representations of Alzheimer’s disease
- P3.2. Saïda Sakali (Belgium): Dementia-friendly municipalities: How can we transform our towns, villages and neighbourhoods by strengthening the social fabric around people with dementia and their carers?
• P3.3. Maddalena Riva (Italy): Knowledge and attitudes about Alzheimer's disease in the lay public: influence of caregiving experience and other socio-demographic factors in an Italian sample

11.00-12.00 (Green Room) Parallel Session P4: Successful campaigning
Chairperson: Sabine Jansen (Germany)
• P4.1. Jessica Federer (Germany): Successful campaigning: collaborations with industry
• P4.2. Michael Hagedorn (Germany): Konfetti im Kopf – a photographic awareness campaign
• P4.3. Alice Jarratt (United Kingdom): Policy and pressure: making dementia strategies a reality
• P4.4. Michael Splaine (USA): Special populations, special policy challenges

13.00-14.00 (Blue Room) Special Symposium SS1: Day-to-day decisions on dementia: Discussing challenges and sharing insights with an expert panel
Chairperson: Giuseppe Bruno (Italy)
• Expert panel from across Europe including healthcare professionals, a carer and a representative from a patient advocacy group
This symposium has been organised and funded by Pfizer Ltd

13.00-14.00 (Yellow Room) Oral poster presentations OP
Chairperson: Charles Scerri (Malta)
• OP1. Razvan Ioan Trascu (Romania): Alzheimer diagnostic challenges: Romanian healthcare system flaws
• OP2. Areti Efthymiou (Greece): Results of a cognitive and physical training programme for people with MCI
• OP3. Paraskevi Sakka (Greece): Dementia screening and memory enhancing project in a population of urban dwelling elderly people
• OP4. Sirkkaaliisa Heimonen (Finland): A journey of possibilities – A logotherapeutic model of dementia care
• OP5. Eric Sanchez (France): A nationwide telephone helpline
• OP6. Michael Spline (USA): Messages and strategies for public health
• OP7. Luiza Spiru (Romania): Professional caregiving and workforce training in Romania
• OP8. Luiza Spiru (Romania): Breakthrough technologies in professional dementia healthcare
• OP9. Ramona Lucas Carrasco (Spain): Consequences of the lack of policies for people with dementia: A case report from Spain

14.00-15.30 (Red Room) Parallel Session P5: Nursing home care
Chairperson: Maria do Rosário Zincke dos Reis (Portugal)
• P5.1. Margrét Gústafsdóttir (Iceland): Enhancing nursing students’ understanding of the experience of a person facing dementia by interviewing a close family member of that person
• P5.2. A.M. van Dijk (Netherlands): The Imagination method; A new approach for caregivers of people with dementia in nursing homes
• P5.3. Anna Renom (Germany): Criteria to determine appropriateness of hospital admission in nursing home residents with dementia: A systematic review
• P5.4. Graínne McGettrick (Ireland): Continuing to care for people with dementia: Irish family carers’ experience of their relative’s transition to a nursing home
• P5.5. Wolfgang Billen (Luxembourg): Organisational and personal determinants of the use of physical restraints in Luxembourg nursing homes

14.00-15.30 (Blue Room) Parallel Session P6: Education and training
Chairperson: Alicja Sadowska (Poland)
• P6.1. Carmen Sinner and Mireille Elsen (Luxembourg): A step out – the practical and social importance of training for people with dementia and their caregivers
• P6.2. Alda Marques (Portugal): Moving beyond training: a psychoeducational programme for formal caregivers of elderly with dementia
• P6.3. Judith Mollard (France): *Education and training of family caregivers: A major challenge for France Alzheimer*
• P6.4. Béatrice Surber (Switzerland): *Improving skills through regular supervision of a group of home carers*

14.00-15.30 (Yellow Room) Parallel Session P7: Supporting and involving people with dementia (1)

**Chairperson: Antonia Croy (Austria)**

• P7.1. Josine van der Poel (Netherlands): *Involving people with dementia in the development of information materials*
• P7.2. David Batchelor and James McKillop (United Kingdom): *The physical effects of dementia*
• P7.3. Aude Dion (Belgium): *The video blog alzheimercafe.be – Giving a voice and a face to people with dementia*
• P7.4. Elisa Virkola (Finland): *The agency of everyday life of people with dementia living alone*

14.00-15.30 (Green Room) Parallel Session P8: Organisation and financing of care

**Chairperson: Clive Evers (United Kingdom)**

• P8.1. Gwendoline Taché (France): *Informal care received by people with dementia aged 75 years and older: empirical evidence from the French National Survey Handicap-Santé Ménages 2008*
• P8.2. Jean-Claude Leners (Luxembourg): *People with dementia and care insurance in Luxembourg – Survey after more than five years*
• P8.3. Staffan Karlsson (Sweden): *European health and social care and welfare systems for persons with dementia*
• P8.4. Jan de Lepeleire (Belgium): *Outcomes COGNOS study - Care for people with cognitive dysfunction - A Belgian national observational study*

16.00-17.30 (Red Room) Symposium S2: Facing dementia together - Professional carers and people with dementia and their carers

**Chairperson: Carine Federspiel (Luxembourg)**

• S2.1. Iva Holmerová (Czech Republic): *Care approaches in Eastern European countries*
• S2.2. Kaisu Pitkälä (Finland): *A rehabilitative approach to dementia care*
• S2.3. Christina Kuhn (Germany): *End-of-life care for people with dementia – An evaluation of two innovative approaches in Luxembourg*
• S2.4. Dianne Gove (Luxembourg): *Ethical implications of assistive technologies in residential care settings*

6.4.3 Saturday, 2 October 2010

09.00-10.30 (Red Room) Symposium S3: Facing dementia together - Doctors and researchers & people with dementia and their carers

**Chairperson: Sigurd Sparr (Norway)**

• S3.1. Francesca Cerreta (United Kingdom): *Bringing new treatments and diagnostic procedures to patients – Understanding the drug development process*
• S3.2. Philippe Amouyel (France): *European collaboration on dementia research: the Joint Programming Initiative*
• S3.3. Bengt Winblad (Sweden): *New treatments for people with dementia – Current research approaches*
• S3.4. François Blanchard (France): *Addressing ethical questions in dementia research*

11.00-12.00 (Red Room) Parallel Session P9: Innovative Care services and approaches (2)

**Chairperson: Pat Doherty (Ireland)**

• P9.1. Christian Gilles (Belgium): *ARDM: an expanding network devoted to people with dementia in a Belgian rural area*
• P9.2. Matthias W. Riepe (Germany): Are quality criteria for memory clinics needed? A statement from the European Memory Clinics Association (EMCA)
• P9.3. Areti Efthymiou (Greece): Caring for the carer: Project “Life after care”
• P9.4. Luisa Bartorelli (Italy): The savvy caregiver programme – An intervention on family members of Alzheimer patients Assistance and support (Institutional care)

11.00-12.00 (Blue Room) Parallel Session P10: Assistive technologies and design

Chairperson: Luiza Spiru (Romania)

• P10.1. Lisa van Mierlo (Netherlands): DEMENTELCOACH: Effect of telephone coaching on informal and professional carers of community dwelling people with dementia
• P10.2. Laura Sorri (Finland): Helping the elderly with memory disorders to orientate in built environment – a field study of a technological system
• P10.3. Jon Boon (United Kingdom): Designing for dementia

11.00-12.00 (Yellow Room) Parallel Session P11: Rights and ethics

Chairperson: Dianne Gove (Luxembourg)

• P11.1. Elisabeth Bourkel (Luxembourg): Perceived rights and stigmatisation of people with Alzheimer’s disease
• P11.2. Henna Nikumaa (Finland): Are people with dementia equal in the Finnish social security system?
• P11.3. Astrid Schmitz (Germany): Management perspective of a European research project: ethical committee’s approval and fair authorship allocation
• P11.4. Jan Killeen (United Kingdom): Dementia: autonomy and decision-making - principles into practice

11.00-12.00 (Green Room) Parallel Session P12: The international dimension of dementia

Chairperson: António Oliveira Costa (Portugal)

• P12.1. Frank J. Schaper (Australia): In dementia care – Is Australia the lucky country?
• P12.2. Marc Wortmann (United Kingdom): Global impact of dementia
• P12.3. Siew Li Cheung and Kelvin Koh (Singapore): An innovative inpatient rehabilitation ward for persons with dementia in a community hospital in Singapore
• P12.4. Amir Parsa (USA): Arts engagement programmes for people with dementia and their caregivers

13.00-14.00 (Blue Room) Special Symposium SS2: PharmaCog: Bringing new hope to patients with Alzheimer’s disease

Chairperson: Elaine Irving (United Kingdom)

• Elaine Irving (United Kingdom): PharmaCog: Alzheimer’s drug discovery from bench to bedside
• Esther Schencker (France): Getting the dose right
• David Bartres-Faz (Spain): Sorting the good from the bad
• Alexandra Auffret (France) and Elaine Irving (United Kingdom): Towards designing better clinical studies

13.00-14.00 (Yellow Room) Special Symposium SS3: Vorstellung der “Association Luxembourg Alzheimer“ mit Schwerpunkt der Pflegeoase „Beim Goldknapp“

• Alain Tapp (Luxemburg) und Michèle Halsdorf (Luxemburg)

14.00-15.30 (Red Room) Parallel Session P13: Non-pharmacological approaches to the management of dementia

Chairperson: Paraskevi Sakka (Greece)

• P13.1. Anne Hanno (Finland): Dance and movement as a tool - education in Summer University of Pohjois-Pohjanmaa
• P13.2. Nomiki Karpathiou (Greece): “The past recaptured” - A personal webpages reminiscence programme
• P13.3. Ivo Cilesi (Italy): Doll therapy, non-pharmacological treatments for the management of BPSD (behavioural and psychological symptoms of dementia) in subjects with Alzheimer’s dementia
• P13.4. Katarína Karolová (Slovak Republic): Cognitive training as a non–pharmacological approach in comprehensive care and treatment of patients with Alzheimer’s disease
• P13.5. Anouk Dufour (Belgium): Home Ergotherapy: Supporting the person with Alzheimer’s disease and his/her family

14.00-15.30 (Blue Room) Parallel Session P14: Screening, diagnosing and treating dementia

Chairperson: Magda Tsolaki (Greece)

• P14.1. Patricio García Báez (Spain): Computational intelligence methods for automatic diagnosis of dementia
• P14.2. Manfredi Ventura (Belgium): A survey of physicians’ perceptions of adherence to oral cholinesterase inhibitor treatment in patients with Alzheimer’s disease
• P14.3. Eugenia Papalexi (Greece): Memantine in everyday clinical practice: Comparisons of data from observational studies in Greece and in Germany
• P14.4. Magali Perquin (Luxembourg): MemoVie: Prospective evaluation of neuropsychological and biological characteristics of mild cognitive impairment and of associated subclinical health problems
• P14.5. Armelle Desplanques-Leperre (France): Increasing the quality of care of behavioural disorders in Alzheimer’s disease and reducing the use of neuroleptics for a better quality of life

14.00-15.30 (Yellow Room) Parallel Session P15: Supporting and involving people with dementia

Chairperson: Julie Fraser (Luxembourg)

• P15.1. David L. W. Buglar (United Kingdom): The Influence of consumer involvement on dementia research: A case study of the UK Alzheimer’s Society
• P15.2. Sabine Jansen (Germany): People with dementia – part of the community
• P15.3. Sirkkaliisa Heimonen (Finland): Supporting persons with dementia through peer group discussions
• P15.4. Kristiina Karttunen (Finland): Neuropsychiatric symptoms and quality of life in patients with very mild and mild Alzheimer’s disease

14.00-15.30 (Green Room) Parallel Session P16: National dementia strategies

Chairperson: Annette Dumas (Belgium)

• P16.1. Maija Juva (Norway): The National Dementia Plan – where are we now?
• P16.2. Luiza Spiru (Romania): Alzheimer’s disease in Romania: the national programme for prevention, prediction, personalised treatment and monitoring of memory diseases
• P16.3. Wendy M. Werkman (Netherlands): Integrated dementia care effective from a client’s point of view
• P16.4. Charles Scerri (Malta): Societal, pharmacotherapeutic and policy aspects of dementia care in the Maltese islands
• P16.5. Paraskevi Sakka (Greece): Towards a dementia action plan in Greece

16.00-17.30 (Red Room) Symposium S4: Facing dementia together - The dementia community and policy makers

Chairperson: Maurice O’Connell (Ireland)

• S4.1. Antoni Montserrat (European Commission): European initiatives in the field of Alzheimer’s disease and other dementias
• S4.2. Heike von Lützau-Hohlbein (Germany): Dementia as a national priority: An overview of dementia strategies
• S4.3. Jeannot Krecké (Luxembourg): The care sector as an economic and employment factor
• S4.4. Gerrit Rauws (Belgium): A societal response to dementia

17.30-18.00 (Red Room) Closing Ceremony
Closing comments and farewell by

- Liane Kadusch-Roth, Association Luxembourg Alzheimer
- Chairperson-elect of Alzheimer Europe

Presentation and invitation to 21st Alzheimer Europe Conference in Warsaw
6.5 Annex 2: Evaluation report of AE Conference in Luxembourg

6.5.1 Conference participants

6.5.1.1 Breakdown by country

Luxembourg 79  
Greece 32  
UK 30  
France 25  
Belgium 23  
Switzerland 14  
Germany 13  
Italy 13  
USA 13  
Finland 11  
Ireland 7  
Netherlands 6  
Norway 6  
Romania 5  
Sweden 5  
Israel 4  
Spain 4  
Australia 3  
Iceland 3  
Portugal 3  
Singapore 3  
Lithuania 2  
Slovakia 2  
Austria 1  
Canada 1  
Cyprus 1  
Czech Republic 1  
Ghana 1  
Korea 1  
Malta 1  
Monaco 1  
Nigeria 1  
Poland 1  
Turkey 1  
Uganda 1  

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6.5.1.2 Breakdown by category

Health or social care professionals 112  
Alzheimer association staff and volunteers 78  
Academics/Researchers 49  
Industry representatives 29  
Other 25  
Policy makers/Civil servants 13  
Persons with dementia/carers 12  

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6.5.2 Evaluation and feedback

In total 57 feedback forms were received. These were filled in and returned by:

- 27 health or social care professionals
- 17 volunteers or staff members of an Alzheimer association
- 7 carers
- 3 people with dementia and
- 4 other

6.5.2.1 Plenary sessions

The various plenary sessions were rated as follows:

<table>
<thead>
<tr>
<th></th>
<th>Poor</th>
<th>Adequate</th>
<th>Good</th>
<th>Very Good</th>
</tr>
</thead>
<tbody>
<tr>
<td>Opening ceremony</td>
<td>2.27</td>
<td>13.64</td>
<td>47.73</td>
<td>36.36</td>
</tr>
<tr>
<td>Plenary 1</td>
<td>3.92</td>
<td>13.73</td>
<td>37.25</td>
<td>45.10</td>
</tr>
<tr>
<td>Plenary 2</td>
<td>8.33</td>
<td>22.92</td>
<td>45.83</td>
<td>22.92</td>
</tr>
<tr>
<td>Plenary 3</td>
<td>2.04</td>
<td>26.53</td>
<td>55.10</td>
<td>16.33</td>
</tr>
<tr>
<td>Plenary 4</td>
<td>-</td>
<td>19.44</td>
<td>47.22</td>
<td>33.33</td>
</tr>
</tbody>
</table>

Recommended speakers:

- Winblad Bengt 14
- McKillop James 9
- Ferring Dieter 8
- Hughes Julian 7
- McKillop Maureen 7
- McGettrick Grainne 6
- Amouyel Philippe 5
- Gove Dianne 4
- Montserrat Antoni 2
- Isaac Maria 1
- Kuhn Christina 1
- Raws Gerit 1

6.5.2.2 Parallel sessions

<table>
<thead>
<tr>
<th></th>
<th>Poor</th>
<th>Adequate</th>
<th>Good</th>
<th>Very Good</th>
</tr>
</thead>
<tbody>
<tr>
<td>Topics chosen</td>
<td>1.82</td>
<td>20.00</td>
<td>47.27</td>
<td>30.91</td>
</tr>
<tr>
<td>Quality of presentations</td>
<td>3.57</td>
<td>35.71</td>
<td>51.79</td>
<td>8.93</td>
</tr>
<tr>
<td>Duration of presentations</td>
<td>3.57</td>
<td>32.14</td>
<td>51.79</td>
<td>12.50</td>
</tr>
<tr>
<td>Time for discussion</td>
<td>26.79</td>
<td>35.71</td>
<td>26.79</td>
<td>10.71</td>
</tr>
</tbody>
</table>

Recommended speakers:

- Damian Murphy 3
- Razvan Ioan Trascu 3
- Michael Hagedorn 2
- Luisa Bartorelli 1
- Wolfgang Billen 1
- John Boon 1
- Judith Fox 1
- Anja Leist 1
- Stephanie Levi 1
- Alda marques 1
- Judith Mollard 1
- Anna Remon-Guiteras 1
6.5.2.3 Social programme

<table>
<thead>
<tr>
<th></th>
<th>Poor</th>
<th>Adequate</th>
<th>Good</th>
<th>Very Good</th>
</tr>
</thead>
<tbody>
<tr>
<td>Welcome Reception</td>
<td>2.17</td>
<td>6.52</td>
<td>43.48</td>
<td>47.83</td>
</tr>
<tr>
<td>Gala Dinner</td>
<td>-</td>
<td>-</td>
<td>54.55</td>
<td>45.45</td>
</tr>
<tr>
<td>Coffee breaks</td>
<td>1.79</td>
<td>3.57</td>
<td>41.07</td>
<td>53.57</td>
</tr>
<tr>
<td>Lunches</td>
<td>1.79</td>
<td>1.79</td>
<td>19.64</td>
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6.5.2.4 Conference venue and organisation

<table>
<thead>
<tr>
<th></th>
<th>Poor</th>
<th>Adequate</th>
<th>Good</th>
<th>Very Good</th>
</tr>
</thead>
<tbody>
<tr>
<td>Online registration</td>
<td>6.25</td>
<td>16.67</td>
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<td>Conference website</td>
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<td>30.19</td>
</tr>
<tr>
<td>Welcome desk</td>
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<td>50.91</td>
<td>32.73</td>
</tr>
<tr>
<td>Conference venue</td>
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<td>12.24</td>
<td>42.86</td>
<td>42.86</td>
</tr>
<tr>
<td>Staff friendliness</td>
<td>3.45</td>
<td>3.45</td>
<td>29.31</td>
<td>63.79</td>
</tr>
<tr>
<td>Orientation and sign-posting</td>
<td>12.50</td>
<td>14.29</td>
<td>44.64</td>
<td>28.57</td>
</tr>
<tr>
<td>Meeting room for pwd</td>
<td>18.75</td>
<td>18.75</td>
<td>34.38</td>
<td>28.13</td>
</tr>
<tr>
<td>Conference material</td>
<td>1.85</td>
<td>9.26</td>
<td>48.15</td>
<td>40.74</td>
</tr>
<tr>
<td>Translation</td>
<td>11.36</td>
<td>13.64</td>
<td>43.18</td>
<td>31.82</td>
</tr>
<tr>
<td>Exhibition</td>
<td>-</td>
<td>43.59</td>
<td>43.59</td>
<td>12.82</td>
</tr>
</tbody>
</table>

6.5.3 Comments and suggestions

6.5.3.1 Plenary and parallel sessions

6.5.3.1.1 Positive

- second and third speaker S3 very good
- like experiences and stories from PWD
- SS2 good
- the presentation of Ioan Trascu was very clear and interesting (communication with Alzheimer Patients). It was particularly interesting and useful for people who have a PWD in their family

6.5.3.1.2 Negative

- Too many speakers, short moments, just a small opportunities for discussions
- first presentation S3 poor
- beaucoup de statistique mais pas d’approche par rapport a la situation au terrain. Trop abstractes et se basant sur des statistiques « douloureuses ». cf Billen : mauvaise image par rapport aux « missing word » au Luxembourg mais qui ne représente pas la réalité absolue.
- Besoin de plus de discutions concernant les PWD et leur entourage. Pas grand-chose concernant des projets longs termes sur le sujet des PWD et leurs aidants.
- Il y avait de bonnes choses mais beaucoup trop d’information données pendant les deux jours et les informations étaient décevantes.
- too many speak in bad English, difficult to understand.
• This tool is not appropriate for an evaluation of the parallel sessions in general you have to note each speaker
• presentation about ongoing studies without data to show are a waste of time (usually)
• I found the quality of most presentation poor, boring because read out loud from paper, spoken quickly, no eye contact with public and sometimes hard to understand their English
• Maria Isaac has a poor diction, very difficult to understand her spanglish, to avoid for future conference.
• P.2 no discussion at all, poor chairing from Sabine Henry
• P4.4.useless as too preliminary
• Unfortunately many presentations were so much difficult to understand for people who don’t speak English fluently

6.5.3.1.3 Suggestions

• Please do not allow speakers to read their ppt out loud, the ppt should support, not be the text spoken.
• Some parallel sessions could be presented by each person in his/own language, and the chairperson would translate
• let carers tell their stories
• more time for small group discussion around topics
• Judith Fox – insights on caring, methods, focussed on dignity and empowering as far as possible her partner.
• Preparing the public-it will affect them, info is reactive more then proactive
• there should be more dementia patient and their carers input into the conference
• would really like the see/hear more from people with dementia
• need to have clearer guidelines for speakers at workshops; too much detailed info presented, not overly relevant to the audience. I know this is a challenge but it would be better to tailor it to the audience’s needs
• Discussion panels would be appreciated to break to powerpoints and add opinions
• relevance of presented topics (eg. Background information of European research project) to audience should be checked

6.5.3.2 Social programme

6.5.3.2.1 Positive

• Excellent, really brilliantly organised
• you are on the right track and I’m sure the gala diner will be just as good, thank you.
• the service was impeccable no need for improvement
• excellent food, breaks, etc…thank you!

6.5.3.2.2 Negative

• open buffet might not have been a good idea, too much wine
• information about Luxembourg and the city missed
6.5.3.3 Suggestions

- Coffee breaks may be complemented with fruits
- please invite the PWD to the Gala diner (this time we were 6 people)
- proposer du café dès 8h au matin pour les personnes qui viennent plus tôt (transport en commun)
- bitte vor beginn des programms schon kaffee bereitstellen
- coffee at 9 am is good
- coffee after lunch
- prepare more vegetables for salad bar (there weren't enough for everybody)
- Serve coffee at the tables during lunchtime
- why not Luxembourgish specialties, like riesling paté
- a real coffee machine for espresso and cappuccino would have been appreciated
- a small drink on Friday and Saturday after the last presentation
- better coffee (espresso)

6.5.3.3 Conference venue and organisation

6.5.3.3.1 Positive

- Particularly liked the images and quotes in the programme book a lot, and save the date boxes throughout.
- good job, well done!
- I think everything was very satisfactory

6.5.3.3.2 Negative

- Technique standard was too poor during several sessions; too much time was used to get the sound on picture on place. This was particularly disturbing during P7.2 in the yellow room on Friday.
- Please have a look what room is defined, here loud, noisy and others using it
- Signing to parallel rooms could have been better; Staff did not know rooms by colour coded reference, room maps/directions not shown until the stairs
- on the website were missing information about the venue, Luxembourg and travel to Luxembourg. PDW room seemed to still be in a busy area, as I'm not a PWD I don't know if it was a problem.
- the meeting room for PWD was not very quiet and was used by others
- I found it very disturbing that the location of the speaker and their presentation are far apart (red room)
- technique was poor and too often did not work
- venue very good but not dementia friendly, meeting room for PWD was not quiet enough, not a closed room and used by others, not respected by the other participants
- the meeting room for people with dementia was very poor; it was not a quiet area. Non dementia people were using the room; the room was an open plan with a lot of noise from the main area
- the venue is really nice architecturally but it's functionality is questionable, the sound system in the main hall is really poor, the screens are difficult to see/fuzzy/visibility very poor. IT and IT support very weak!
6.5.3.3 Suggestions

- Fixed microphones to be replaced by hand held microphones
- Put information about which presentations will be in another language then English in the programme.
- improvement on computer technique
- translation in every room
- more translation of presentation in the other rooms
- a list of names of the people attending!!
- less presentations and less technical problems (sound and video)
- PPT slides need to be adapted to the bigger screens, colours and contours made them very hard to read
- Inform participants of possible public transportation (bus) + location of the conference venue (map)
- Organize abstract in programme book in chronological order if possible
- information on the website about registration, location of the venue, programme was incoherent, confusing and difficult to find
- list of attendees, more info about the venue on the conference website
- not a conference every year
- a more central location, more shopping and dining options, better / more smoker-friendly areas, conference centre = Hotel (no need to walk or drive to attend)
- technicians or assistant to transfer the ppts well in advance, before the presentation not all PPTs could be opened on the conference laptops!
- It would have been welcome to indicate how to come here from the airport (which bus, etc...)
- more info to handle step by step for online registration. More visibility and signs (conference venue hard to find) the entrance!

6.5.3.4 Other comments

- As always my experience of these European events is the coming together of a “family” I always enjoy.
- Je suis déçu du contenu de la conférence, il n'y avait rien d'innovant et je n'ai rien appris de nouveau au cours du congrès.
- more publicity for all people, would be good against taboo. (I think she might mean that more noise around dementia and more campaigning to raise awareness would break the taboo, and stop stigmatization)
- Perfect! Thanks!
- -Very positive to give patients and carers a voice, they are our voice
- -thank you very much for the opportunity to participate to the conference
- -absolutely wonderful conference, informative, engaging, and very enjoyable! Thank you for the work that went into such a great meeting

6.5.4 Final verdict

Asked whether they would recommend an Alzheimer Europe Conference, the breakdown was as follows:

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>yes</td>
<td>90.57</td>
</tr>
</tbody>
</table>
7 Organisational issues

7.1 Aims

A number of organisational issues will also be addressed in the 2010 Work Plan to improve the organisation's activities in the future, such as the development of a new strategic plan (2011-2015) based on the results of a membership satisfaction survey, continued membership development and contacts with Alzheimer association in countries not currently covered by the organisation, the development of strategic partnerships with other organisations active in the field and the organisation of a European Dementia Summit, a statutory review and the development of a financial diversification strategy.

7.2 Achievements and results

7.2.1 Membership satisfaction survey and new strategic plan

After the successful implementation of its 2003-2006 Business Plan and its 2006-2010 Strategic Plan, Alzheimer Europe felt it important to assess the views of its membership on past activities and projects before developing a new Strategic plan.

85% of the member organisations of Alzheimer Europe participated in a survey to assess the satisfaction of members with past activities. The responses were overwhelmingly positive and all past activities were rated as “Excellent” or “Good” by over 70% of AE’s members. A number of activities scored even higher and the following activities were all rated as “Excellent and “Good” by over 90% of the membership:

- The Paris Declaration on the political priorities of the European Alzheimer movement,
- Alzheimer Europe’s campaign to make dementia a European priority,
- The organisation’s communication tools including the monthly e-mail newsletter, the Dementia in Europe magazines and the website,
- The inventory of legislation on healthcare decision making by people with dementia,
- The comparison of social support systems as part of the EuroCoDe project,
- The report and position on advance directives,
- The recommendations and report on end-of-life care for people with dementia.

For the development of its strategic plan, Alzheimer Europe opted for continuity in light of the positive feedback on its past activities. For the period 2011-2015, the organisation identified the following key strategic objectives:

1. Making dementia a European priority,
2. Supporting policy with facts,
3. Basing our actions on ethical principles and
4. Building a stronger organisation.

The new strategic plan was presented at the Annual General Meeting in Luxembourg and welcomed by the members with a view of adopting the document in 2011.

7.2.2 Membership development

After the acceptance of Alzheimer associations from Croatia, Estonia and Slovenia as members in 2009, Alzheimer Europe now covers the vast majority of Member States of the European Union (with the exception of Hungary, Latvia and Lithuania).
At the same time, Alzheimer Europe established informal contacts with associations in Hungary, Latvia and Lithuania and involved them where possible in its projects and activities.

In 2010, Alzheimer Europe also welcomed the Italian association “Alzheimer Uniti” as a provisional member.

7.2.3 Strategic partnerships

As in previous years, Alzheimer Europe continued its collaboration with a number of other key European organisations with an interest in dementia, such as the European Alzheimer’s Disease Consortium, the European Federation of Neurological Societies, the European Association of Geriatric Psychiatry, the European Union Geriatric Medicine Society, the Interdem network, the European Association for Palliative Care and the International Association of Gerontology – European Region.

As a member of the European Patients’ Forum (EPF), Alzheimer Europe contributed to European discussions on general health and patient related issues such as cross-border health-care or the legislation on information to patients. Alzheimer Europe also participated in an EPF seminar on health technology assessment and EPF’s General Assembly.

Alzheimer Europe also continued its involvement with the Alliance for MRI which was created to address the concerns raised by the impact of a European Directive on the use of MRI for clinical and research purposes and participated in a meeting of the Alliance with members of the Cabinet of EU Health Commissioner John Dalli. The campaign of the Alliance contributed to the European Commission re-examining the directive.

In 2010, Alzheimer Europe also strengthened the contacts with AGE, the European Platform for elderly people with the two organisations collaborating on the preparatory meetings of the Presidency Conferences on Mental Health and Dementia and exchanging information on their respective activities.

7.2.4 Fundraising

In 2010, Alzheimer Europe was able to count on the support of the European Commission which provided an operating grant for Alzheimer Europe’s activities in the framework of the EU public health programme.

In addition, Alzheimer Europe was able to rely on a number of additional income categories, such as membership dues and other contributions from member organisations, direct payments from individuals such as conference registration fees and publication sales, support from foundations and from corporate sponsors in line with the organisation’s guidelines.

Alzheimer Europe continues to disclose all sources of funding in a transparent fashion in line with the guidelines for organisations accredited by the European Medicines Agency.

7.3 Deliverables

7.4.1 Introduction

The current document outlining the strategic priorities of Alzheimer Europe is based on the experiences of the organisation’s past “Business Plan (2001-2005)” and its “Strategic Plan (2006-2010)”.

The document was presented at the Annual General Meeting in Luxembourg on 30 September 2010 after a thorough consultation of the organisation’s members regarding Alzheimer Europe’s past activities and projects and its future priorities.

7.4.2 Objective 1: Making dementia a European priority

7.4.2.1 Representing the interests of people with dementia

As the European organisation representing the interests of people with dementia and their carers, the key aim of Alzheimer Europe is to make dementia a European priority.

As outlined in the Paris Declaration of the political priorities of the European Alzheimer movement, Alzheimer Europe and its member organisations call on European institutions and national governments to recognise dementia as a healthcare priority and to develop European and national dementia action programmes.

<table>
<thead>
<tr>
<th>Key aims and actions (2011-2015)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer Europe will analyse in how far national governments have implemented the priorities contained in the organisation’s Paris Declaration.</td>
</tr>
<tr>
<td>Alzheimer Europe will review the priorities outlined in the Paris Declaration and adopt a new programme of its political priorities.</td>
</tr>
</tbody>
</table>

7.4.2.2 Partnering with European institutions

Alzheimer Europe will continue working towards this aim with all European institutions: the European Parliament, the European Commission and the Council of Ministers.

In particular, Alzheimer Europe will continue to coordinate the European Alzheimer’s Alliance of Members of the European Parliament with an interest in dementia and will ensure adequate representation of the Alzheimer movement in all European initiatives in the field of Alzheimer’s disease and other forms of dementia.

<table>
<thead>
<tr>
<th>Key aims and actions (2011-2015)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer Europe will seek to be closely associated and involved with the European Alzheimer’s initiative and the Joint Programme Initiative.</td>
</tr>
<tr>
<td>AE will aim to have the support of 15% of the Members of the European Parliament (or 110 MEPs) to the European Alzheimer’s Alliance and the organisation’s activities by the end of the mandate of the current European Parliament.</td>
</tr>
<tr>
<td>Alzheimer Europe will update Members of the European Parliament on its campaign activities and priorities at least twice a year and continue organising its successful lunch debates.</td>
</tr>
<tr>
<td>Alzheimer Europe will liaise with future EU Presidencies to ensure dementia will remain on the European agenda. The organisation will also examine the possibility of organising its Annual Conferences in collaboration with forthcoming EU Presidencies.</td>
</tr>
</tbody>
</table>
7.4.2.3 Jointly developing policy

As an interest organisation, Alzheimer Europe will closely follow the legislative agenda of the European institutions and the Council of Europe. Where appropriate, Alzheimer Europe will develop a position on legislative documents and promote its views to the relevant European bodies.

Alzheimer Europe will liaise closely with the European Patients’ Forum in the development of policies in those areas which deal with general patient or carer issues.

In addition to this reactive policy development, Alzheimer Europe will also develop policies or recommendations in areas not covered by any of the European institutions, but which are of particular interest to Alzheimer associations and to people with dementia and their carers. Possible areas of interest to the organisation are:

- Guidelines or recommendations on care interventions
- Recommendations to improve the access by people with dementia and their carers to care services and treatment options
- Policy statements on legal or ethical issues in the dementia field

<table>
<thead>
<tr>
<th>Key aims and actions (2011-2015)</th>
</tr>
</thead>
<tbody>
<tr>
<td>➢ The development and implementation of national dementia programmes will be closely monitored by Alzheimer Europe.</td>
</tr>
<tr>
<td>➢ Alzheimer Europe will set up a public affairs working group with representatives from its national member organisations to monitor national policy developments and coordinate, when possible, European campaigning.</td>
</tr>
<tr>
<td>➢ In collaboration with its members, Alzheimer Europe will develop a model with the key elements of a national dementia strategy.</td>
</tr>
</tbody>
</table>

7.4.3 Objective 2: Supporting policy with facts

In its campaign to make dementia a European priority, Alzheimer Europe has been able to use the results of European projects, such as its “European Collaboration on Dementia – EuroCoDe” project or surveys of carers of people with dementia in different European countries.

Alzheimer Europe will continue to support its campaign with sound scientific data and information.

7.4.3.1 Improving the information exchange between AE, its members and other stakeholders

In this regard, Alzheimer Europe will continue to pursue the objective of its previous strategic plan by improving the information exchange between AE, its members and other stakeholders.

Alzheimer Europe plays an important role in gathering information on scientific breakthroughs and policy developments on a national level. It shares this information with its members and other organisations in its wider network through its quarterly newsletter and through its Internet and Intranet sites.

Alzheimer Europe will pay specific attention to policy developments on a national level and in particular:

- Policy developments of interest to people with dementia and their carers (social support, drug reimbursement, social security systems)
- National Alzheimer plans or programmes
- Research programmes and priorities of national governments.
- Legal developments in the areas covered by the Alzheimer Europe Lawnet projects (legal capacity and incapacity, guardianship, coercive measures, consent, advance directives, disclosure of diagnosis, driving, participation of people unable to consent in clinical trials and research, etc.)

<table>
<thead>
<tr>
<th>Key aims and actions (2011-2015)</th>
</tr>
</thead>
</table>
Alzheimer Europe will continue the publication of its monthly e-mail newsletters and will send it to a significantly expanded list of recipients, including European and national policy makers, Alzheimer associations, researchers and people with dementia and their carers.

The Dementia in Europe Magazine is a key tool for disseminating information on policy developments. By the end of the period, the magazine will be published on a quarterly basis.

The Alzheimer Europe website is another important dissemination tool for the organisation and will continuously be updated.

Alzheimer Europe will develop a members’ only section of its website to simplify the communication with the different working groups of the association. In addition, AE will explore the possibility of using this section for the exchange of information between member organisations.

### 7.4.3.2 Setting up a European Dementia Observatory

In the long term, Alzheimer Europe intends to become the prime information resource for policy developments in the various European countries covered by the organisation. The aim of the organisation is to set up a “European Dementia Observatory” monitoring and disseminating news on scientific breakthroughs and relevant policy developments.

#### Key aims and actions (2011-2015)

- Alzheimer Europe will set up a Scientific Advisory Board which will provide a commentary on important scientific news. Twice a year, Alzheimer Europe will collaborate with the members of the Scientific Advisory Board to publish a Research Digest containing an analysis of the most important scientific developments.

### 7.4.3.3 Comparing national systems and identifying best practices

In order to highlight differences in the access by people with dementia and their carers to care services and treatment options, Alzheimer Europe will carry out surveys involving its national member associations.

Based on the experience of previous projects, such as Lawnet or the social support work package of the EuroCoDe project, Alzheimer Europe will in particular analyse the national situation as regards:

- the financing of long-term care,
- quality criteria for care services,
- legislation regarding driving and dementia,
- training and education of healthcare professionals,
- the support provided by governments to national Alzheimer association and
- the funding of dementia research

By describing and analysing the differences between countries, Alzheimer Europe will identify and promote best practices in the surveyed fields and provide reliable evidence for national organisations to lobby governments.

#### Key aims and actions (2011-2015)

- Where possible, Alzheimer Europe will collaborate with other stakeholders to carry out surveys of people with dementia and/or their carers to identify their needs and understand their experiences in order to base policy recommendations on these findings.
- During the next five years, Alzheimer Europe will also develop a number of comparative reports on key issues identified by the membership.
7.4.4 Objective 3: Basing our actions on ethical principles

Alzheimer Europe's actions and its campaign need not only be based on scientific evidence and facts. It is equally important for the organisation to base its campaigning on clear and shared ethical principles.

The organisation reiterates its commitment to the underlying philosophy of its first business plan which defined Alzheimer Europe’s mission as promoting and supporting the dignity and autonomy of the person with dementia and his/her family throughout the course of the disease.

In the next five years, Alzheimer Europe will therefore prioritise the work of the European Dementia Ethics Network which was started in 2009 thanks to the financial support of the German Ministry of Health.

7.4.4.1 Understanding ethical principles and approaches

Alzheimer Europe will carry out an extensive literature search of positions and recommendations on ethical issues developed by professional, medical and carers associations. The European Dementia Ethics Network will establish reading lists on a number of ethical issues and make these available on the organisation's website. Where possible, the full positions will be included in a searchable database to build up a comparative reference library of existing ethical positions and discussions.

Key aims and actions (2011-2015)

- Alzheimer Europe will expand the membership of the Steering Committee of the European Dementia Ethics Network to ensure an adequate geographical representation of the different European regions.
- The participation of people unable to consent in research, the value and disclosure of a diagnosis of dementia, the ethical dilemmas faced by carers of people with dementia in day to day situations and the ethical implications of clinical trials will be the priority areas for the organisation’s in depth literature reviews.

7.4.4.2 Promoting a rights-based approach to dementia

People with dementia and their carers continue to face stigma and social exclusion. The inclusion of people with disabilities in society and in all activities has however been highlighted by a number of international documents, such as the 2006 UN Convention on the Rights of Persons with Disabilities. These documents highlight people with disabilities (including people with dementia) as subjects with rights rather than the objects of charity, medical treatment and social protection.

Alzheimer Europe will promote this rights based approach and advocate for greater inclusion of people with dementia and their carers.

Key aims and actions (2011-2015)

- Alzheimer Europe will analyse how the principles enshrined in the UN Convention on the Rights of Persons with Disabilities can be applied to persons with dementia and campaign for the recognition of dementia as a disability.

7.4.4.3 Finding common ground and building consensus

On identified priority areas, the secretariat will carry out a more in-depth literature search and develop a report with the findings of the literature search. These reports will highlight the areas where ethical positions diverge, as well as areas where a consensus exists. These reports will be made available on the network’s website.

Key aims and actions (2011-2015)

- Alzheimer Europe will set up working groups with ethical experts on the four subjects identified above (the participation of people unable to consent in research, the value and disclosure of a diagnosis of dementia, the ethical dilemmas faced by carers of people with dementia in day to day situations and the ethical implications of clinical trials).
Alzheimer Europe will aim to develop consensual positions on these issues which are supported by its member organisations.

7.4.5 Objective 4: Building a stronger organisation

Alzheimer Europe needs to continuously strengthen the organisation and ensure its operational capacities (including staff and finances) can achieve the ambitious aims and objectives of its Strategic Plan.

In addition, Alzheimer Europe will develop annual Work Plans based on this strategic plan which take into account the financial situation of the organisation.

7.4.5.1 Supporting and involving national Alzheimer associations

In all its activities, Alzheimer Europe will ensure to involve its membership. Members will also be asked to assess the initiatives and projects of Alzheimer Europe on a continuous basis, in order to ensure they meet the expectations of national member organisations.

When selecting members of working groups and steering committees, Alzheimer Europe will ensure that different member organisations will be involved and able to participate.

**Key aims and actions (2011-2015)**

- Alzheimer Europe will identify and work with Alzheimer associations from all Member States of the European Union.
- Alzheimer Europe will continue to involve representatives of national organisations in all activities in particular the organisation’s campaign to make dementia a European priority.
- Workshops will be organised at AE Conferences to promote the exchange of information and experiences between associations on organisational issues, such as campaigning, public affairs or awareness raising.
- Alzheimer Europe will review its membership policy and develop clear criteria to allow for a fair representation of national associations.

7.4.5.2 Involving people with dementia and their carers

Alzheimer Europe is above all the umbrella organisation of national Alzheimer associations. At the same time, the organisation has provided a voice for people with dementia at its Annual Conferences and has successfully involved and consulted people with dementia in various working groups and projects.

Alzheimer Europe will also ensure that the voice of carers is adequately represented at the different levels of the organisation.

**Key aims and actions (2011-2015)**

- Alzheimer Europe will continue to involve and consult people with dementia and their carers in its conferences and working groups.
- A working group of people with dementia from different European countries will be set up by the organisation and Alzheimer Europe will establish clear terms of reference for the working methods of the group as well as for membership within the group.
- The working group of people with dementia will elect a representative to act as a full member of the Alzheimer Europe Board.
- Alzheimer Europe will ensure (former) carers of people with dementia and people with dementia constitute the majority in the organisation’s governing bodies.
7.4.5.3 Establishing Alzheimer Europe Conferences as unique networking opportunities

Alzheimer Europe has a long tradition of organising annual conferences. The audience of its conferences is unique though as it mostly attracts representatives from Alzheimer association, professional carers, care researchers and of course people with dementia and their carers. Alzheimer Europe will not compete with other long established conferences which mainly attract health care professionals and medical researchers.

Rather, a long-term conference concept will be developed which will make the Alzheimer Europe Conference the prime conference on dementia care, dementia ethics and dementia policy in Europe.

### Key aims and actions (2011-2015)
- Alzheimer Europe will develop a long term concept for Alzheimer Europe Conferences.
- Alzheimer Europe will alternate between holding larger Conference covering care, ethics and policy and smaller thematic conferences dedicated to an in-depth exploration of a specific subject. In each case, an Annual General Meeting will be organised in conjunction with the Conference.

7.4.5.4 Developing strategic partnerships

Alzheimer Europe will develop strategic partnerships with other organisations active in the dementia field. Particular attention will be paid to forging closer ties with scientific organisations and associations of health and social care professionals.

In order to promote the dialogue with members of the professions involved in dementia care, Alzheimer Europe will organise yearly meetings with the presidents of the European scientific societies of psychiatrists, neurologists, psychologists, general practitioners, geriatricians, nurses, etc. Alzheimer Europe will also develop its contacts with relevant professional organisations involved in social care and the social sciences.

Similarly, Alzheimer Europe will attend the yearly meetings of relevant scientific organisations in order to promote the interests of people with dementia and their carers and to present the positions and activities developed by the organisation.

### Key aims and actions (2011-2015)
- Alzheimer Europe will establish partnership agreements with a number of scientific and professional organisations, including but not limited to the European Alzheimer’s Disease Consortium, the Interdem network, the European Federation of Neurological Societies and the European Association of Geriatric Psychiatry.
- Alzheimer Europe will develop associate membership status for professional and academic organisations with an interest in dementia.

7.4.5.5 Providing a sound governance structure

The Board of Alzheimer Europe plays an active role in steering and monitoring the organisation’s activities as well as its financial commitments.

In addition, important policy statements are adopted by the membership at large and Alzheimer Europe has adopted clear guidelines on how positions can be adopted without convening formal meetings.

### Key aims and actions (2011-2015)
- Alzheimer Europe will review its statutes and rules and regulations to identify areas where improvements could be made.
7.4.5.6 Diversifying the organisation’s funding

Any organisation needs to rely on stable funding for its activities. Whilst Alzheimer Europe has been able to rely on a variety of sources of income, it has yet to secure long term funding which is not prone to fluctuations or differences from one year to the next.

Key aims and actions (2011-2015)

- Alzheimer Europe will campaign for the inclusion of Alzheimer’s disease as a funding priority of the public health programme and for operating grants to be provided for the organisation’s activities.
- Alzheimer Europe will develop a long term funding strategy and identify specific funding streams for its various activities and projects.
- Alzheimer Europe will review the membership fee structure to take better account of the financial situation of its members rather than their geographical situation.
- Alzheimer Europe will investigate the possibility of asking for subscriptions for its Dementia in Europe magazine and other publications.
- The concept for Alzheimer Europe conferences will need to ensure conferences generate a small financial return for the organisation.
## Annex: Meetings organised and attended in the framework of the 2010 Operating Grant

### 8.1 Meetings organised by Alzheimer Europe in the framework of the 2010 Operating Grant

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>8 March</td>
<td>AE Working group on the ethical implications of assistive technologies</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>9 March</td>
<td>Steering Committee of the European Dementia Ethics Network</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>26 April</td>
<td>AE Board meeting</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>21 June</td>
<td>AE Board</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>22 June</td>
<td>European Parliament lunch-debate; &quot;Alzheimer’s disease and dementia as a national priority&quot;</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>6 September</td>
<td>Strategy meeting of AE Board</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>22 September</td>
<td>AE Working group on the ethical implications of assistive technologies</td>
<td>Berlin, Germany</td>
</tr>
<tr>
<td>22 September</td>
<td>Steering Committee of the European Dementia Ethics Network</td>
<td>Berlin, Germany</td>
</tr>
<tr>
<td>30 September</td>
<td>AE Board meeting</td>
<td>Luxembourg, Luxembourg</td>
</tr>
<tr>
<td>30 September</td>
<td>AE Annual General Meeting</td>
<td>Luxembourg, Luxembourg</td>
</tr>
<tr>
<td>1-2 October</td>
<td>20th Alzheimer Europe Conference</td>
<td>Luxembourg, Luxembourg</td>
</tr>
<tr>
<td>6 December</td>
<td>AE Board meeting</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>7 December</td>
<td>European Parliament lunch-debate; &quot;The Joint Programming of Research in neurodegenerative diseases&quot;</td>
<td>Brussels, Belgium</td>
</tr>
</tbody>
</table>

### 8.2 Meetings attended by AE staff in the framework of the 2010 Operating Grant

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>11 January</td>
<td>EMEA Workshop on “New developments in dementia of Alzheimer’s type”</td>
<td>London, United Kingdom</td>
</tr>
<tr>
<td>19 January</td>
<td>Launch of RightTimePlaceCare project</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>10-12 March</td>
<td>Alzheimer’s Disease International Conference</td>
<td>Thessaloniki, Greece</td>
</tr>
<tr>
<td>23 March</td>
<td>Meeting with Novartis</td>
<td>Geneva, Switzerland</td>
</tr>
<tr>
<td>31 March</td>
<td>Meeting with International Longevity Centre</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>27-28 April</td>
<td>EFGCP Workshop “Ethical challenges in clinical research at both end of life”</td>
<td>Antwerp, Belgium</td>
</tr>
<tr>
<td>5 May</td>
<td>Recognition Meeting</td>
<td>Berlin, Germany</td>
</tr>
<tr>
<td>6 May</td>
<td>Patients’ Rights Day in European Parliament</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>8-9 June</td>
<td>100 Year Anniversary Meeting of Karolinska Institutet</td>
<td>Stockholm, Sweden</td>
</tr>
<tr>
<td>28-29 June</td>
<td>Spanish Presidency Conference on the mental health of elderly people</td>
<td>Madrid, Spain</td>
</tr>
<tr>
<td>3 September</td>
<td>Meeting with AGE</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>16 September</td>
<td>Annual Conference on Ligue Alzheimer</td>
<td>Louvain-la-Neuve, Belgium</td>
</tr>
<tr>
<td>5-9 October</td>
<td>European Health Forum “Health in Europe, ready for the future”</td>
<td>Hof Badgastein, Austria</td>
</tr>
<tr>
<td>28 October</td>
<td>European Parliament Committee on Public Health Hearing on Alzheimer’s disease</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>3-4 November</td>
<td>Steering Committee of “Value of Diagnosis” project</td>
<td>London, United Kingdom</td>
</tr>
<tr>
<td>8 November</td>
<td>EMEA Expert meeting on familial neurodegenerative diseases</td>
<td>London, United Kingdom</td>
</tr>
<tr>
<td>16 November</td>
<td>International Longevity Centre meeting in</td>
<td>Brussels, Belgium</td>
</tr>
</tbody>
</table>
25-26 November | EU Presidency Conference “Improving the quality of life of people with dementia: A challenge for European society” | Brussels, Belgium
29-30 November | EMEA meetings with patient organisations | London, United Kingdom
8-11 December | APFADA Conference: Alzheimer’s disease: towards an integrated policy | Lisbon, Portugal

**8.3 Other meetings attended by AE staff in 2010**

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>7 January</td>
<td>Meeting with Alzheimer’s Society</td>
<td>London, United Kingdom</td>
</tr>
<tr>
<td>12 January</td>
<td>Health Consumer Powerhouse meeting “How to cure the EU Patient Information Gap”</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>12 January</td>
<td>Hearing of Commissioner-designate Viviane Reding</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>18 January</td>
<td>Meeting with Association Luxembourg Alzheimer</td>
<td>Luxembourg, Luxembourg</td>
</tr>
<tr>
<td>20 January</td>
<td>Meeting with EFPIA representatives</td>
<td>Brussels, Belgium</td>
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<tr>
<td>4 February</td>
<td>EFPIA think tank</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>18 February</td>
<td>Meeting with Association Luxembourg and Université de Luxembourg</td>
<td>Luxembourg, Luxembourg</td>
</tr>
<tr>
<td>23 February</td>
<td>European Parliament Carers Interest Group</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>25 February</td>
<td>Meeting with Foundation Compassion Alzheimer Bulgaria</td>
<td>Luxembourg, Luxembourg</td>
</tr>
<tr>
<td>2 March</td>
<td>Family Platform Info Day in European Parliament</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>3 March</td>
<td>Eurofound Seminar “Company strategies in Europe: Flexibility and social dialogue”</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>7 April</td>
<td>Meeting with Luxembourg-Congrès</td>
<td>Luxembourg, Luxembourg</td>
</tr>
<tr>
<td>12 April</td>
<td>Meeting with Antoniya Parvanova, MEP (Bulgaria)</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>27 April</td>
<td>EFPIA think tank</td>
<td>Brussels, Belgium</td>
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<tr>
<td>27 April</td>
<td>European Parliament Employment and Social Affairs Committee</td>
<td>Brussels, Belgium</td>
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<tr>
<td>28 April</td>
<td>European Parliament Mental Health Interest Group</td>
<td>Brussels, Belgium</td>
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<tr>
<td>28 April</td>
<td>European Parliament Industry Committee</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>28 April</td>
<td>European Parliament Internal Market Committee</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>4 May</td>
<td>Belgian Presidency Expert meeting on dementia</td>
<td>Brussels, Belgium</td>
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<tr>
<td>4 May</td>
<td>European Parliament Environment and Health Committee</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>6 May</td>
<td>Patients’ Rights Day in European Parliament</td>
<td>Brussels, Belgium</td>
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<tr>
<td>11 May</td>
<td>STOA Meeting on Ageing Research</td>
<td>Brussels, Belgium</td>
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<tr>
<td>13 May</td>
<td>Meeting with Pfizer</td>
<td>Luxembourg, Luxembourg</td>
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<tr>
<td>18 May</td>
<td>European Patients’ Forum Seminar on Health Technology Assessment</td>
<td>Brussels, Belgium</td>
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<tr>
<td>19 May</td>
<td>General Assembly of European Patients’ Forum</td>
<td>Brussels, Belgium</td>
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<tr>
<td>25 May</td>
<td>Meeting with European Patients’ Forum</td>
<td>Brussels, Belgium</td>
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<tr>
<td>3 June</td>
<td>Meeting with Elena Oana Antonescu, MEP (Romania)</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>3 June</td>
<td>Meeting with Emilia Romana, European Parliament</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>11 June</td>
<td>Meeting with Marisa Matias, MEP (Portugal)</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>12 June</td>
<td>European Memory Clinics Association</td>
<td>Basel, Switzerland</td>
</tr>
<tr>
<td>22 June</td>
<td>European Parliament Women’s Committee</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>23 June</td>
<td>University of Maastricht debate on health literacy</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>7 July</td>
<td>European Commission seminar on Ageing and Women’s Health</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>8 July</td>
<td>Meeting with Alliance for MRI and Cabinet of EU Health Commissioner</td>
<td>Brussels, Belgium</td>
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<tr>
<td>Date</td>
<td>Meeting</td>
<td>Location</td>
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<tr>
<td>1 September</td>
<td>Parliament Magazine reception</td>
<td>Brussels, Belgium</td>
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<tr>
<td>14 September</td>
<td>Meeting with Servier</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>22 September</td>
<td>EFPIA Think tank</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>28 September</td>
<td>European Parliament Carers Interest Group</td>
<td>Brussels, Belgium</td>
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<tr>
<td>1 October</td>
<td>Meeting with Nutricia</td>
<td>Luxembourg, Luxembourg</td>
</tr>
<tr>
<td>10 October</td>
<td>Alzheimer Café Day of Ligue Alzheimer</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>11 October</td>
<td>European Commission workshop &quot;Healthy ageing, adaptation of health systems&quot;</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>13 October</td>
<td>Meeting with Servier</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>13 October</td>
<td>Meeting with Bristol-Myers-Squibb</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>13 October</td>
<td>Meeting with Alzheimer’s Society (UK)</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>20 October</td>
<td>Meeting with office of Marina Yannakoudakis, MEP (United Kingdom)</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>25 October</td>
<td>Meeting with office of Nessa Childers, MEP (Ireland)</td>
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</tr>
<tr>
<td>26 October</td>
<td>Meeting with Lilly</td>
<td>Brussels, Belgium</td>
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<tr>
<td>27 October</td>
<td>United Nations Human Rights Office Seminar on “Human rights of persons in institutional care”</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>28 October</td>
<td>Meeting with office of Glenys Willmott, MEP (United Kingdom)</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>15 November</td>
<td>Meeting with Pfizer</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>17 November</td>
<td>AGE Conference on elderly abuse</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>18 November</td>
<td>EFPIA Think tank</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>24 November</td>
<td>Meeting with AGE</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>30 November</td>
<td>European Parliament Environment and Public Health Committee</td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>30 November</td>
<td>Council of Europe seminar on decision making regarding medical treatment in end-of-life situations</td>
<td>Strasbourg, France</td>
</tr>
<tr>
<td>8 December</td>
<td>Meeting with Sanofi-Aventis</td>
<td>Brussels, Belgium</td>
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</tbody>
</table>