





# *Alzheimer Europe Report*



**The ethical issues linked to the use of  
assistive technology in dementia care**



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## *Introduction*



In this document, Alzheimer Europe presents its position and guidelines on the ethical use of assistive technology (AT) 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 AT (based on an extensive review of the literature) which addresses not only possible disadvantages and ethical dilemmas 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. Whilst we consider that assistive technology should be first and foremost for the benefit of people with dementia, we highlight where appropriate the implications, both positive and negative, on informal and professional carers.

This 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.

As Chair of Alzheimer Europe, I would like to thank all members of the working group (Dianne Gove, Inger Hagen, Sirkkaliisa Heimonen, Stefánia Kapronczay, James and Maureen McKillop, Maria McManus, Alistair Niemeijer, Päivi Topo and Luiza Spiru) of which I was also a member. The working group, which was led by Dianne Gove, Information Officer of Alzheimer Europe, actively sought relevant literature, drafted specific parts of the text reflecting their particular expertise and experience, debated controversial issues and provided detailed comments on the whole document. Their expertise and experience was mainly in the domain of AT development, service provision and organisation, ethics, IT, research in the field of ethics and AT, old age psychiatry, nursing, working for Alzheimer associations, caring, having dementia and using AT. Without the members of the working group, it would not have been possible to produce such a comprehensive report.

The whole project was carried out within the framework of the Dementia Ethics Network and this was the first topic to be addressed in detail. This document on the ethical use of AT for/by people with dementia was approved by the Steering Committee of the Dementia Ethics Network whose members I would also like to thank for their support and expertise in the domain of ethics and in some cases their contribution to the work on the topic of AT (Jean Georges, Alain Franco, Cees Hertogh, Celso Pontes, Christian Beringer, Cornelia Reitberger, François Blanchard, Iva Holmerová, Kati Juva, Malou Kapgen, Mary Marshall, Matthias von Schwanenflügel, Michael Schmieder, Sabine Jansen, Sigurd Sparr) as well as Magda Aelvoet and Bénédicte Gombault from the Roi Baudouin Foundation in Belgium.

I am proud of our approach and the outcome of our work and believe that this text will be informative, useful and thought provoking. I hope that it will contribute towards the ethical use of AT for/by people with dementia and would welcome any feedback from

you concerning your own experience, recent developments in the field of AT and ethics, and ideas concerning the ethical use of assistive technology.

Finally, I would like to thank the German Ministry of Health and the European Commission for their financial support for this project which made it possible to carry out this important work and to publish the results.

Heike von Lützu-Hohlbein  
Chair  
Alzheimer Europe





*Background information  
about dementia, disability  
and assistive technology*

# 1 *Background information about dementia, disability and assistive technology*

This report is about the ethical issues linked to the use of assistive technology for or by people with dementia. We will therefore start in section 1.1 by explaining what dementia is, covering different perspectives and ways of understanding dementia.

As dementia is, amongst other things, a potential disability, we will then briefly examine different approaches to understanding disability and make the distinction between impairment and disability. Accepting that dementia is a potential disability means recognising the potential benefits of assistive technology in helping prevent or minimise the impact of impairment on the daily lives of people with dementia.

## 1.1 Dementia

### 1.1.1 From a medical perspective

Dementia is defined in the DSM-IV<sup>1</sup> and DSM-IV Text Revision as a syndrome characterised by the development of multiple cognitive deficits including memory impairment accompanied by at least aphasia, apraxia, agnosia or a disturbance in executive functioning (Cummings, 2007). This means that the typical signs and symptoms associated with dementia include memory problems along with difficulties with language and understanding, recognising and using objects appropriately, sensory-perceptual difficulties involving one or more senses, and making or adapting plans.

Another classification system for dementia is the International Classification of Diseases and Related Health Problems (ICD) of the World Health Organisation. Both classifications mention a decline in memory loss and of other abilities to such a degree that they interfere with a person's daily life (Whalley and Breitner, 2009).

The neuropathological features of what came to be known as Alzheimer's disease (which is the most common form of dementia) were described in 1907 by Alois Alzheimer. Originally, the term Alzheimer's disease was only used to refer to certain cases which would have previously fallen into the category of pre-senile dementia (with symptoms occurring in people in their 40s to 50s). Symptoms occurring in people over 60 years of age were considered signs of senile dementia or senility which was considered a natural part of ageing (Cahill et al., 2007). However, this distinction based on age was eventually dropped when Katzman (1978) discovered the same plaques and tangles which were characteristic of pre-senile dementia of the Alzheimer's type in the brains of people with senile dementia.

Consequently, in the bio-medical model of dementia, which has for some time been the standard paradigm, Alzheimer's disease is considered as being characterised by a distinct neuropathology in the brain (Cummings, 2007; Gaines and Whitehouse, 2006; Katzman et al., 1978), thereby separating it from other (non-organic) mental disorders and from normal ageing. A typical description of Alzheimer's disease is provided by Cummings (2007, p.3):

*“Alzheimer’s disease (AD) is a progressive neurodegenerative disorder with characteristic clinical and pathological features. Alzheimer’s disease is aetiologically heterogeneous and can be produced by mutations of chromosomes 21, 14 and 1 as well as by as yet unrecognized causative factors.... Pathologically, characteristic findings include neuronal loss, neurofibrillary tangles, neuritic plaques and amyloid angiopathy...”*

Behavioural disturbances as well as psychological, psychotic and psychological signs (such as hallucinations, “wandering” and repetitive questioning) are often interpreted in the bio-medical model as being direct consequences of neurological impairment.

Extensive work on post-mortem brains demonstrated the difference in pathology between the brains of people with dementia and those without (Tomlinson Blessed and Roth, 1970; Homer, 1988). However, Snowden (1997) found no direct correlation between neurological impairment and the symptoms of dementia. In one of the few studies involving the post mortem analysis of the brains of 209 people over the age of 80 and 90 (the Medical Research Council/MRC CFAS, 2001), insufficient difference was found between the brains of people with AD and those without (solely in terms of neuropathology).

36% of people with dementia in the study had low plaque scores or no plaques, whereas 33% of people in the no-dementia group had moderate or severe neuritic plaques. Moreover, only 13% of the people in the no-dementia group had a so-called normal brain. The European Federation of Neurological Societies states in its recommendations on the management and diagnosis of Alzheimer’s disease that, save one remarkable exception, there is no specific biological marker for degenerative dementias and that the aetiological diagnosis of dementias can only be made in terms of probability (Waldemar et al., 2007).

### **1.1.2 The impact of dementia on the daily lives of people with dementia**

Leaving aside the debate about plaques, tangles and normal or abnormal ageing, the symptoms of Alzheimer’s disease can affect people’s everyday lives. Most people with dementia will at some time experience difficulties with memory, reasoning, understanding and communication. Some may have difficulty with orientation in time and in space, some may become confused, have difficulty recognising people or using and manipulating everyday objects and some may misplace things. Such difficulties may eventually make it difficult to hold down a job, drive safely, fulfil social roles and manage everyday tasks such as shopping, washing and dressing appropriately and paying bills. Behavioural and emotional changes may occur which other people may find disturbing such as clinging and following, developing delusions, making false accusations, being apathetic or depressed etc. In addition, some people with dementia will have difficulties with gait, their sleep-wake cycle may be disturbed and in the late stages they may have problems with incontinence.

There may be differences in the experience and expression of dementia depending on the individual, the stage of dementia and also the type of dementia. People with dementia with Lewy bodies, for example, may experience detailed and convincing hallucinations, some of the symptoms of Parkinson's disease, fluctuating abilities and a greater risk of falling or fainting (Alzheimer's Society, 2008). People with fronto-temporal dementia may have relatively intact memory especially in the early stages but have difficulty empathizing with others, behave inappropriately, be easily distracted and develop rituals (Alzheimer's Society, 2009). Finally, people with dementia may have different coping skills and different needs. This long description of possible symptoms and possible difficulties, which is in no way comprehensive, must of course be put in perspective.

### 1.1.3 A more holistic concept of dementia

People with dementia will not all experience all these symptoms and not all to the same degree either. They will have good and bad days (Chester and Bender, 1999) and many will continue to live active, meaningful lives for many years after diagnosis. Moreover, the symptoms of dementia cannot be solely explained in terms of neuropathology but must take into account psychosocial factors (Gubrium, 1986; Kitwood, 1993, Lyman, 1989; Macquarrie, 2005; Sabat, 2001; Snyder, 1999). Kitwood (1993) claimed that the progression of dementia was not determined solely by the changes in the person's brain but rather by a complex interaction between five factors (which is different for each person). Please see below.

*Figure 1: Kitwood's model/equation for dementia*

$$SD = P + B + H + NI + SP$$

(Kitwood, 1993, p.541)

Key: SD = clinical manifestation of dementia; P = personality (in the sense of resources for action); B = biography; H = health; NI = neurological impairment; SP = social psychology

He also highlighted the possibility of "rementing" whereby, under favourable conditions, a person with dementia might show improvements in wellbeing and/or cognitive performance. Examples of rementing challenge the medical model of dementia in that once neurological impairment has occurred and cognitive ability is affected, there should be no improvement other than that brought about by medical treatment.

Kitwood not only provides a more holistic model of dementia which highlights the interaction between neurological impairment, the psychology of the person with dementia and the social environment, but also strongly advocates for the respect of the personhood of the person with dementia. The person is not considered simply as a biological entity or the bearer of the condition but as someone who is at risk of losing their personhood.

- It is therefore important to recognise that people with dementia have impairments but that their behaviour, wellbeing and capacity cannot be solely reduced to such impairments. This opens up the possibility to take measures to reduce the extent of possible resulting disability and one way to do this is through the use of appropriate assistive technology (AT). The difference between impairment and disability will be explained in the following section.

## 1.2 Impairment and disability

Having looked at the different ways that dementia has been and in some cases still is perceived and understood, in this section we will consider a similar development with regard to disability.

### 1.2.1 Medical and social models of disability

Just as there is a medical model of dementia, so too is there a medical model of disability according to which disability is an abnormal individual limitation resulting from impairment. It is considered a feature of the person; something that was caused by disease, trauma or a health condition (WHO, 2002a). Following this line of thought, disabled people must therefore be helped to overcome their limitation or adjust in order to conform to societal norms (Cameron, 2007). In other words, the problem is seen as residing in the individual and the solution in the provision of medical treatment or other interventions. This is not Alzheimer Europe's opinion.

According to the social model of disability, on the other hand, many of the problems faced by disabled people (including people with dementia) are due to the way that society is organized which is rigid and inflexible, and does not meet their needs. Disability is therefore "the product of the physical, organisational and attitudinal barriers present within society, which lead to discrimination" (Open University, 2006).

In the Graz Declaration on Disability and Ageing (EASPD, 2006), for example, it is acknowledged that many disabling conditions are caused by society. Examples of this might include:

- the use of computer touch screens for various transactions,
- the replacement of humans with self-service systems (for washing cars, renting bicycles, filling one's car with petrol and checking out at the supermarket),
- codes and passwords to be remembered,
- abstract signs on public facilities,
- commercial packaging which does not provide an explanation of the contents.

Such factors are often so taken for granted that any problem linked to their use is considered as residing in the individual and not society. On the other hand, it would be a



mistake to consider disability as entirely socially created and not in any way an attribute of the individual (WHO, 2002a).

### 1.2.2 Impairment and disability

Nevertheless, whilst a person may have various impairments, it is often the organisation of society which creates excess disability, combined with certain attitudes and behaviour which Kitwood (1990) and Sabat (1994) describe as a “malignant social psychology” (examples of which include treachery, disempowerment, infantilisation, intimidation, labelling, stigmatization, outpacing, invalidation, banishment and objectification). The following definition of excess disability highlights the distinction between impairment and disability. According to Brody et al. (1971), excess disability is:

*“The discrepancy which exists when the individual’s functional incapacity is greater than that warranted by the actual impairment. In short, it denotes a gap between actual function and judged potential function. It was assumed that the excess disabilities could be attributed to treatable physical, psychological, and/or social factors and that they could exist in any of those spheres.” (Brody et al., 1971, pp. 125-126 quoted in Werezak and Morgan, 2003)*

A practical example of how an impairment can become a disability is provided by Ezeiza et al. (2008) who explain that a person who has a visual impairment becomes a person with a visual disability when he or she needs to read an important text which other people could read but he or she cannot (e.g. instructions on how to exit a building in case of fire). If the person with the visual impairment had access to a text-to-speech instrument, that specific problem in that specific situation would disappear. His or her impairment would remain but through the use of AT, he or she would have access to the same information available to other people. Another way to ensure that certain impairments are not turned into disabilities is by manipulating the environment (e.g. making public areas “wheelchair friendly” through wider doors, ramps and lower public reception desks). Cognitive impairments may be less visible but equally disabling.

Failure to recognise dementia as a potential disability may contribute towards seeing “the problem” as residing in the person with dementia and overlooking the way that other people contribute towards it (i.e. turning cognitive impairment into disability). It also has implications for the attribution of responsibility with regard to possible solutions. This was explained by Kitwood in the following way (emphasis taken from the original text):

*“We are basically sound, undamaged, competent, kind. **They** are in a bad way, for they are afflicted with a primary degenerative disease in the grey matter. **They** are thus damaged, de-railed, deficient. .../... In the long run, **they** will have to learn to accommodate themselves to the provision that we make for them”*

(Kitwood, 1992, reproduced in Baldwin and Capstick, p. 133).

### **1.2.3 Moving away from the medical and social models of disability**

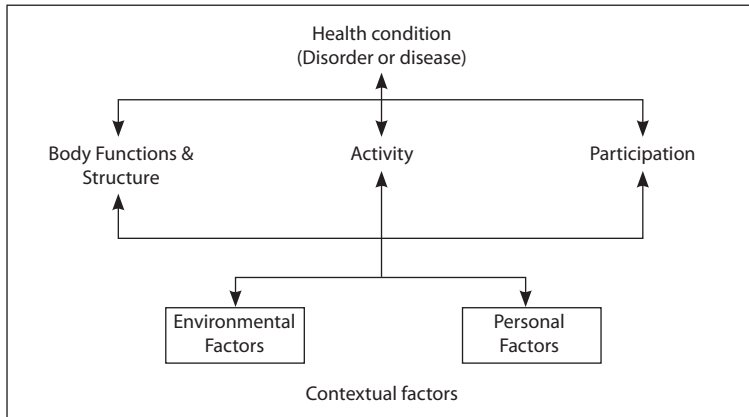
Feminist perspectives on disability have been influential in challenging the preeminence assigned to normalcy, strength and independence, and the devaluation of disability and of people with physical and cognitive impairments, as well as fighting for inclusiveness and valuing the experience of disabled people (Silvers, 2009; Wendell, 1996). This approach helps ensure that the emphasis on the role of society (e.g. in the social model of disability) is not seen as supporting the belief that physical differences and restrictions are entirely socially created (Morris, 1991) which would amount to a denial of people's real experience of their minds and bodies and the significant impact that this may have on their lives.

According to the Convention on the Rights of Persons with Disabilities and its Optional Protocol which was adopted by the United Nations General Assembly on 13 December 2006 and came into force on 3 May 2008, people with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others. Many people with dementia fall into this category. In an introduction to the Convention, the United Nations describe a "paradigm shift" in attitudes and approaches to people with disabilities with a move away from viewing people with disabilities as "objects" of charity, medical treatment and social protection towards viewing them as "subjects" with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society (United Nations, 2009). This perception of disability avoids over-emphasis on the medical factors as well as on the role of society, and it gives a more prominent place to the individual as a unique person and equal citizen.

### **1.2.4 Towards a biopsychosocial model of disability**

The biopsychosocial model of disability, upon which the International Classification of Function, Disability and Health of the World Health Organization is based, integrates the medical and social factors of disability (as Kitwood did in his model of dementia). It represents a biological, individual and social perspective of disability and functioning, whereby alongside the medical condition (disorder or disease) and possible impairments, there are contextual factors linked to the environment and the person. Those linked to the environment might include people's attitudes, buildings, systems and legal and social structures whereas personal factors might include age, gender, experience and coping styles etc. This has been represented in connection with the ICF as follows.

Figure 2: the biopsychosocial model of disability (WHO, 2002a)



- Disability can be reduced or overcome in a number of ways (e.g. by changing attitudes, providing therapeutic interventions, developing coping skills, adapting the environment or practices and through assistive technology). This report is mainly concerned with the use of assistive technology.

## 1.3 Assistive technology

### 1.3.1 What is assistive technology?

#### 1.3.1.1 Definitions

Assistive technology (AT) is the term used to describe devices or systems which allow people to perform tasks which they would otherwise be unable to do, or to increase the ease and safety with which tasks can be performed (Royal Commission on Long-Term Care, 1999). This could include “any item, piece of equipment, product or system, whether acquired commercially, off-the-shelf, modified or customized, that is used to increase, maintain or improve capabilities of individuals with cognitive, physical or communication disabilities” (Marshall, 2000).

Although frequently referred to as assistive technology (and in the past as rehabilitation technology or technical aids), this does not necessarily mean that devices or equipment all use the very latest technology or are extremely complicated or technical to use or install. Mary Marshall (2000) draws attention to the low-level technologies - the “DIY store” end of the market, which includes things that can be purchased in high street stores, through the Internet etc. such as basic movement detectors, carbon monoxide sensors, light and motions sensitive night lighting and anti-flood devices. The benefits of low-level technology are classed as being readily available for purchase, being able to be used in the person’s existing home, not requiring the installation of sophisticated computer equipment and that they can be easily removed or adapted as the needs of the person with dementia

change. An important feature of many of these devices is that once installed they do not require the user to do anything (i.e. they are passive). Consequently, provided that they are suited to each person's capacities, they are ideal for people with dementia who might otherwise forget to use them or have difficulty operating them.

### **1.3.1.2 Goals of technology in the field of dementia care**

In the next decade, technology will become more and more important in our ageing society and in the care of people with dementia. Developing towards sophisticated 'ambient intelligence technology', the technological devices of the future will be neither active nor passive, but essentially interactive and allow for personalised applications and personalised use, although the question of who will be the user of technology will be more difficult to answer, as these new technologies will play their role often unobserved by the people who profit from them. However, a categorisation can be made between assistive and surveillance technology.

Sometimes AT is categorised as being assistive or for surveillance, or alternatively as promoting autonomy or offering protection. A distinction is sometimes made between assistive devices that are active and enabling and technology involving monitoring or controlling that is passive with a protective function, with the former being more applicable to community dwelling people and the latter being more applicable to people with dementia in residential care. This distinction is further linked to perceived differences in the degree of decision-making capacity between community dwelling people with dementia and those in residential care in that more people in residential care are likely to have a higher degree of incapacity and consequently the technology is actually used on their behalf by professional carers. However, one of the promises of technology is to promote independent living and postpone nursing home admission, to the effect that in the near future people with more advanced stages of dementia and higher degrees of incapacity can still be cared for at home.

In practice, there is often no clear boundary between the two types of technology as depending on its use, the situation and a number of factors, assistive devices may offer some degree of protection and similarly, surveillance devices may be enabling and promote autonomy. Consequently, many devices involve elements of both. Nevertheless, although there is a continuum between both applications of AT, the extremes of this continuum are not morally equivalent (Hertogh, 2010).

AT can be further divided into different categories according to its overall purpose. It could, for example, be described as being:

- for recreational and social purposes,
- supportive (helping people to perform tasks),
- responsive (helping manage risk and raising alarms when necessary) or
- preventative (helping prevent dangerous risks and again if necessary raising alarms).

To a certain extent, the above categories could also be understood as reflecting a continuum moving from the principle user being the person with dementia to the principal user being the carer. Moreover, not all forms of AT for people with dementia are used by people with dementia because, as mentioned above, some forms are passive. However, the “assistive” part of the term “assistive technology” indicates that they assist someone and this person should be the person with dementia. If they also happen to make some aspect of daily life a little easier for other people, all the better but this should not be the main aim.

The type of device or system needed and the ability of the person with dementia to use it will change as the disease progresses. In some cases, the device will be used by a carer<sup>2</sup> rather than the person with dementia (e.g. in the case of lifting equipment). Devices and systems which are intended to be used directly by people with dementia must take into account the nature of their condition, their cognitive and possible physical impairments, environmental factors and individual factors such as stress levels, coping skills and ability to adapt.

### **1.3.1.3 Concrete examples of assistive technology**

Examples of AT include:

- devices to remind a person of the date and appointments, to facilitate communication or to take medication,
- smoke, water overflow and gas detectors,
- electronic tracking devices or tele-alarm systems linked to a whole support network of trained personnel, ready to intervene in case of emergency,
- computer-assisted devices which can be used to encourage social interaction and stimulate the senses such as reminiscence programmes using touch screen technology, and
- socially assistive robotics (a developing area which is in its early stages (more details are provided in Chapter 3).

An area of AT that is becoming more common is the “smart home” which has been described by Orpwood (2001) as a building which provides intelligent interaction with the occupants to make their lives that bit easier. Smart homes contain smart technology which may involve automatic or user-initiated communication by means of various appliances, sensors and switches (Cash, 2003) (e.g. to ensure that bathwater is not too hot, or that the cooker has been switched off, or movement detectors which switch on a light or alert a carer if someone gets out of bed).

#### **1.3.1.4 Where is assistive technology used?**

AT is often associated with the home environment. Astell (2006), for example, describes AT as “a range of technological interventions, typically within the home environment, to assist and support people with dementia to carry out activities of daily living.” However,

2 The term “carer” will be used in this report to refer to a person who takes care of someone with dementia on an informal basis (i.e. it is not part of their paid employment even if in some countries some carers receive a small payment from the government in recognition of their valuable work). Often carers are relatives but this is not always the case which is why we do not use the term “family carer”. In most cases, they did not choose to become a carer but circumstances of life resulted in them becoming one. People who care for people with dementia in the context of paid employment will be referred to as professional carers. Sometimes, to clearly differentiate between the two types of carers we will use the terms “informal carer” and “professional carer”. This distinction does not imply any difference in the quality of care provided by either.

the home environment can be interpreted as including people's own homes as well as residential care settings. Certain devices are specifically designed to facilitate freedom of movement outside the confines of the home but the focus is nevertheless on enabling people to move around and, most importantly, to return safely to their homes.

Being able to drive is often associated with independence and quality of life. For this reason, people with dementia are often reluctant to give up driving. Some attention has been paid to problems encountered by older drivers (e.g. using complex visual displays) and the need to develop satellite navigation systems which do not rely solely on "distance to turn" instructions but rather incorporate landmarks (e.g. external reference points such as traffic lights, pedestrian crossings, petrol stations and distinctive pubs) to indicate the need to turn (May et al., 2005). This reduces the time spent looking at the screen (which tends to be longer for older drivers) and the need to estimate distances and may make it easier to plan and follow routes. This study was not tested on people with dementia but the future development and adaptation of such existing technology could perhaps eventually benefit those in the early stages who still have sufficient driving capacity.

Nevertheless, according to Blackman et al. (2003), the lack of published guidelines on the design of outdoor dementia-friendly environments seems to reflect a presumption that the lives of people with dementia are "home-based," although they acknowledge that there are greater technical difficulties in trying to control outdoor environments.

### **1.3.2 What are the potential benefits of assistive technology?**

#### **1.3.2.1 *Enabling/promoting autonomy and wellbeing***

AT can be beneficial to people with dementia in that it can support and facilitate their memory, orientation and other cognitive abilities (e.g. enabling them to continue doing things for themselves). This may help them to remain active and continue living in their own homes and in a familiar social environment, and to maintain meaningful occupations and valued social/family roles. This may, in turn, further preserve their remaining capacities which is important for self-esteem.

AT has the potential to promote independence, autonomy and wellbeing. Studies have shown that AT has proven useful for people with dementia and their carers (Cahill et al, 2007; Hagen et al. 2005; Macijauskiene et al, 2006; Topo et al, 2007). AT may, in some cases, contribute towards peace of mind for carers linked to safety concerns, repeated questioning and passivity. The increased autonomy, for example linked to people with dementia being able to use a cooker, find keys and go out alone, may help reduce some of the strain and worry that many carers experience. The cost effectiveness (Woolham, 2005) and cost-benefit (Duff and Dolphin, 2006) of implementing assistive technologies (mostly simple stand-alone devices) have also been shown.

However, benefits can only be described as potential because everyone is different and has their own history, personality and living situation. Usefulness is clearly dependent on a multitude of factors related, for example, to the person with dementia, the carer, the

relationship between the two, the device or system itself and the environment. Moreover, AT is often provided in combination with additional expertise and forms of care and it is this overall care package which is beneficial (Marshall, 1999).

People with dementia in residential care may also benefit from AT. Whilst there are professional carers available to assist them with activities of daily living, the use of certain devices and equipment may help them to retain some of their capacities longer, at some point combining AT with human assistance before eventually becoming dependent on others for certain tasks.

#### **1.3.2.2 *Providing protection and a safe environment***

Some devices serve as a safety net to enable people with dementia to reduce the possibility of accidents occurring such as scalding themselves, causing fires, floods or explosions, or falling in the dark etc. This is achieved by the installation of devices which either automatically control certain aspects of the home environment or provide simple warnings whenever the person is at risk. In such cases, the benefits may be threefold: firstly, for the people with dementia for reasons already discussed; secondly, for carers in that it may provide them with peace of mind and reduce stress and thirdly, for professional carers in residential care settings who may be freed to concentrate on other aspects of care such as social interaction.

Freedom of movement is closely linked to the issue of safety and includes the freedom to walk about freely and to leave one's home or care establishment without fear of punishment but also to get in and out of bed or a chair without restriction (such as rails, fold-down trays or straps). AT can provide a means of monitoring and controlling exits or areas which make it possible for a person to move about freely and safely. This is one area of AT which also raises important ethical issues which will be discussed in Chapter 3 of this report.

It is necessary to find the right balance between ensuring safety and fostering independence. Sometimes, there may be conflicting views between people with dementia, carers and professional carers about which should take precedence.

#### **1.3.2.3 *Contributing towards quality of life and social inclusion***

AT is not limited to providing a safe environment and promoting independence. It may also contribute towards respecting people's dignity and right to privacy, improving communication, breaking isolation, providing leisure activities and generally promoting quality of life and personal wellbeing.

People with dementia, carers and professional carers may have different priorities when it comes to the use of AT and see different benefits in it, partly based on their different experiences, roles and interests. A review carried out by Topo (2009) found that studies reported a greater concern amongst carers about safety issues and managing activities of daily living (Kirsi et al., 2004; Pollitt et al., 1991) compared to the concerns of people with dementia which were more about finding meaningful activities, managing to

sleep and living with the insecurity of disorientation in time and space (Harris, 2006). The interests and concerns of people with dementia linked to the use of AT should not be neglected due to the paternalistic attitudes and behaviour of others.

#### **1.3.2.4 Benefits in the context of professional and/or residential care**

Godwin (2008) points out that the needs of professional carers are often given insufficient attention with the result that people with dementia may end up being moved into more restrictive residential facilities. Consequently, it is important to explore the use and benefit of AT for all concerned and not just for the sole benefit of the person with dementia even though the use of AT should, first and foremost, be for the benefit of people with dementia.

The use of AT for older people may also be beneficial to health and social care organisations in that it may reduce the need for beds in acute and long-term care, and for personal assistance at home, although research to support this claim is unfortunately lacking (with the exception of client case studies and a study using a cross-sectional survey design) (Beech and Roberts, 2008).

Whilst there is a risk that AT will be used to replace human care, it is also possible that it might lead to a reduction in the level of stress amongst professional carers, thereby enabling them to provide more person-centred care (Marshall, 1997) and as previously mentioned, increased social contact. This is important as some carers have expressed concerns that AT might replace human contact (Sävenstedt et al., 2006).

#### **1.3.3 Assessing the possible benefits of AT**

Assessing the benefits of AT in general is difficult as AT is usually part of an overall care package, often accompanied by a network of support staff. Consequently, a more pragmatic approach to the assessment of benefit, incorporating a range of methodologies, is needed (Beech and Roberts, 2008). In the context of the ENABLE project, technology seemed to play an important role in enabling people to remain living independently for longer than those who did not have access to it. This benefit did not seem to be based on factors such as age, the degree of dementia, other participant characteristics or a larger care package but rather on motivation, relation to the carer and factors related to the product and the environment (ENABLE, 2004).

It must also be borne in mind that there may be differences of opinion and that some people with dementia may accept or choose a specific device or system, whereas their spouses might not (or vice versa). Also, studies to assess the perceived benefits of AT should ideally involve people who have consented to its use but unfortunately, this might be a biased sample. Lilja et al. (2003) found that elderly people with disabilities who accepted care supported by AT were more positive about the perceived benefits of it compared to those who did not want to have it. They also more readily accepted the necessity to modify their living environment compared to those who did not want any disruption of their home and life.



However, a small-scale study involving 20 people with dementia and their carers in Ireland recorded mixed reactions to the use and benefits of AT (Cahill et al. 2007). Five types of AT were tested and evaluated. Dissatisfaction was expressed with three devices (the automatic night lamp, the gas cooker monitor and lost item finder) due to technical difficulties and carers reported having to remind the person with dementia to use the devices. The night-and-day calendar and the picture telephone were very popular whereas the lost item finder was considered more useful by one of the carers than it was by the person with dementia for whom it was intended. This study was part of the ENABLE project in which 80 people with dementia and their carers in 5 countries completed an assessment study for at least 3 months. Numerous scientific articles concerning the results of the whole study are available (for more information, please see: <http://enableproject.org/download/Enable%20-%20Scientific%20articles.pdf>).

Sävenstedt et al. (2010) argue that research into the perceived usefulness of assistive technology neglects the views of people with dementia who have communication difficulties or replaces their voice for that of the carers despite the fact that some researchers have shown that it is possible to obtain meaningful data from people with dementia, who have difficulty expressing themselves, by means of adapted interview strategies (Moore and Hollett, 2003). An alternative or additional method of assessing usefulness and user-friendliness of AT is through observation. Using a combination of different methods of data collection can also be beneficial and provide a much fuller understanding of the possible benefits of AT. There is no need to rule out quantitative methods of data collection (e.g. involving structured questionnaires and response scales) which may also be administered effectively provided that they do not take too long and perhaps with the use of oral and visual techniques (Trigg et al., 2007). However, Hagen and Cahill (2009) suggest that randomized controlled trials (RCT), which are a specific type of quantitative study in which one group of people have access to an intervention and another similar group does not, are unethical as they involve knowingly denying a particular vulnerable group access to an intervention which is believed to work and would presumably be beneficial to that group.

The installation or use of devices and equipment can never guarantee specific benefits and can be used in a negative or positive manner. For maximum benefit, it should be adapted to the needs and wishes of the person with dementia, be easy or intuitive to use, the least obtrusive and based on consent.

At the level of the individual, Bjørneby, Topo and Holthe (1999) suggest assessing the possible increased or decreased likelihood of a range of possible outcomes, namely increased/decreased:

- social contact
- self-esteem
- dignity

- quality of life
- independence
- safety

and to consider to what extent these consequences are more or less important to the person with dementia, his/her family and professional carers. This could change as the condition and needs of the person with dementia and even his/her living arrangements change. Finally, when assessing the potential benefits of AT for people with dementia, it is necessary to consider the impact of the technology, of the personal characteristics of the person with dementia, of the family carer(s), of the environment and of the procedure and people carrying out the assessment (Hagen et al., 2004).

Based on a recent review of 66 studies, Topo et al. (2009) conclude that research into the role of technology for people with dementia is still in its infancy, that ways to promote studies looking at the perspectives of people with dementia at home must be found and that national and international multi-disciplinary studies are needed to determine the possibilities and limitations of technology to support people with mild to moderate dementia and their carers living in the community.

#### **1.3.4 Case study demonstrating the organisation, use, benefits and review of AT in the home**

The following case study entitled “Night time at home” by Fiona Taylor provides a real example of how AT was organised and implemented on behalf of an elderly lady in order to enable her to continue living in her own home in a small town in Scotland instead of having to move in to a nursing home. It highlights the benefits of AT and demonstrates how its use was reviewed and adapted to this lady’s needs and lifestyle. The case study is taken from: Taylor, F. (2010), Night time. In *Time for Dementia*, Eds. J. Gilliard and M. Marshall, Hawker Publications, London.

### **“Night time” by Fiona Taylor**

#### **Initial referral**

Mrs Brown was first referred to the social work department by her GP who asked for a “nursing home assessment”. The social worker who was allocated the case felt that this would be a bit hasty, and that they could provide a range of services that could support Ms Brown to live in her own home for some time yet. The initial assessment did however highlight a few significant risks in Ms Brown’s lifestyle.

Ms Brown was 80 years of age and lived alone in the main street of a small town in Scotland. As she was an only child who never married she had no immediate relatives and although she had a few neighbours who helped out now and

again, these too were becoming frailer and less able. Ms Brown had arthritis in her hands which made many ordinary living tasks very difficult and sometimes painful for her, she was also a bit forgetful, but liked to be independent and was not prepared to be told what to do or when to do it.

Ms Brown had worked as a nurse all her life and particularly enjoyed working nights. She always liked the quietness of night time and stated she still found great pleasure in looking out of her window at night at the various constellations, sometimes she even sat in the garden and enjoyed the view on cold winter nights along with a “wee whisky”. As she worked shifts all her life she had what some people would consider to be an erratic sleep pattern and she ate and slept at odd times throughout the day and night. Sometimes she decided not to get dressed and have a lazy day in her pyjamas. And at other times she had a burst of energy and decided to clear out all her drawers and cupboards during the night.

Her memory loss was having some impact on her life and with growing regularity she forgot to take her medication, and then took a few together to make up for the missed ones. She was not quite sure how often she ate, but assured the worker she was well fed and that there was always plenty of chocolate in case she felt hungry. Her neighbours were worried about her being out at night and spoke of the many days when she did not get dressed. The local green grocer, supplied her with her weekly shopping and she always had the payment sitting ready for him. As the post office was only a few doors away she continued to collect her own pension, however when the pavements were icy the owner phoned her and arranged for someone to pop along with it for her.

### **Provision of services**

A home support service was arranged to assist Ms Brown with washing dressing, food preparation and getting ready for bed each night. Visits were arranged 3 times each day, 7 days a week. As an extra precaution the overnight visiting service were alerted and asked to call in if there were lights on in the house. A key safe was fitted to allow the staff easy access.

However, within the first few weeks it became increasingly obvious that the care package was not working. Although there were times when Ms Brown was glad of the help around the house during the day there were other times when she became quite aggressive towards the night support staff and either refused to co-operate or else she put them out of her house. As tensions rose she became quite agitated and was regularly found knocking the doors of neighbours to complain about intruders in her home at all hours of the night.

A case conference was arranged and at that point in time it seemed the most obvious outcome would be an admission into care. However, during the case

discussion one of the student social workers who were in attendance suggested that perhaps assistive technology could be tried to support Ms Brown, as a last resort before arranging an admission to a care home.

### **New care package**

A selection of Passive infra red Beams (PIR) was fitted in the house. These were linked to the local call centre but set with time delay switches. These would inform overnight visiting staff when Ms Brown was actually up, during the night, therefore preventing them popping in when she was sleeping and ensuring she had the opportunity to open the door to them, if she wished.

A PIR reminder light was fitted to her front door. The home support worker activated this when she left in the evening and this reminded Ms Brown *not to go out of the front door, as it was not safe*. These were deactivated by the support staff in the morning as the risks were considerably less during the day and the assessor did not want to prevent her from going out and chatting to neighbours and friends in the local community. Her back door was fitted with a time delay door contact. This meant that if Ms Brown chose to go out at night to sit in her back garden, she could do so, and only if she had not come back in within the hour would the overnight staff be alerted.

As Ms Brown was often quite active during the night clearing out cupboards and tidying up when she felt energetic the overnight visiting service were asked not to interrupt this routine, but to take this opportunity to offer tea and a light snack if they were invited in. This would make up for any meals she would decline the following day when she was tired.

The home support staff that supported Ms Brown during the day and night were provided with *digital pens*<sup>1</sup> this meant that they could send each other a messages to say what she had eaten, whether she had slept and when she was most likely to need support again. In this way the workers could fit in with what suited her best rather than calling in when she had just gone to sleep or making her breakfast shortly after she had just had a snack from the overnight service.

### **Change of support plan**

When the technology was originally installed the technicians had put in place an automatic lighting system. This meant that when Ms Brown arose in the dark, lights were activated that ensured she could find her way to the toilet safely. These would turn themselves off when she was back in bed. However, these were quickly removed as staff soon discovered that Ms Brown became very agitated and could not return to bed when the lights were still on. She was worried, not only about her electric bills but because she wondered who had put the lights on and thought there was someone in her house. Eventually staff found that a touch lamp would provide sufficient lighting to allow her to go to the toi-

let, without having to fiddle with a small switch. She could easily switch this off herself on her return to bed.

Ms Brown continues to enjoy living in her own home with her own routine, and is supported by staff when she needs it.

Source: Taylor, F. (2010), Night time. In *Time for Dementia*, Eds. J. Gilliard and M. Marshall, Hawker Publications, London.

<sup>1</sup> digital pens – these are electronic pens that have a small camera inserted just beside the nib. When someone writes a note or draws a diagram- this is photographed and sent to a pre-programmed mobile phone number. In this case study the digital pen was left in the person's home beside their communication page and the 4 home support staff who regularly provided a service to Ms Brown were given mobile phones to aid their communication.



*AT, ethical issues  
and legislation*

## 2 *AT, ethical issues and legislation*

### 2.1 What do we mean by “ethics” and ethical principles

Broadly speaking, ethics is a branch of philosophy which seeks to address issues related to concepts of right and wrong. One might say that ethics in some ways is about what ought to be, not what is. We simply would not need to consider what we ought to do if we always did it as a matter of course. When focusing on morality and ethics, we are therefore concerned with what morally ought to be the case. Certain ethical principles or obligations that tell us what we ought to do are generally accepted and can be conceived as the expression of normative ethical systems. They are not contingent upon cultural or temporal features such as tradition, religion, or law. For instance, the ethical principle ‘to do no harm’ can be considered as one of those principles, and all ethical theories embrace this principle, though some might put more emphasis on it than others.

There are a few different types of ethics but the one we are interested in is “applied ethics” which applies ethical theories to real life situations. Ethics is relevant to day-to-day care giving and in day-to-day medicine and routine medical decision making. However, new technologies can create situations of insecurity and lack of normative guidance. This is why applied ethics often focuses on controversies and dilemmas, which might erroneously suggest that besides these controversies routine medicine and the care giving are morally neutral.

Philosophical ethics has to a certain degree always been applied to real-life. Aristotle, for example, believed that there was no point in (studying) ethics unless it would have some beneficial effect on the way one lived one’s life - or at least inform one how one ‘ought to live’. But, since the 1950s, there has been a renewed interest in detailed discussion of particular issues of contemporary practical concern. One area in which ethics has always played an important role is medicine, in particular in issues involving life and death. Recently, partly as a result of advances in science and technology, new areas of enquiry have been explored. In addition, certain parts of medical practice which previously lacked their own distinctive ethics have begun to develop them (Crisp, 1998).

Much of applied ethics is concerned with three theories:

1. Deontological ethics: a set of ethical beliefs, in which principles and values are seen by adherents to be self-evident and not in need of more basic proof.
2. Utilitarianism: which is the doctrine which holds that acts are right solely insofar as their consequences maximise general happiness.
3. Virtue Ethics: which emphasises the character of the moral agent rather than rules or consequences, as the key element of ethical thinking, asserting thereby that the right action will be chosen by a suitably ‘virtuous’ agent (Timmons, 2002).

As implied above, ethics cannot be equated with religion, even though many religions advocate ethical behaviour, because ethics applies to everyone whereas religion is limited to certain groups of people (Verlasquez et al., 1987). Neither is it just about doing what feels right or going along with your “gut feeling” as sometimes this might not be what is actually morally right. One cannot rely solely on laws as history has shown that laws sometimes condone unethical behaviour. Similarly, it is not because everyone does something a particular way, that it is right.

People will differ in their opinions as to what is right and wrong. Often they will base their opinions on facts but even facts are often no more than shared points of view about what something is or isn't (HENT, 2002). Often there is no simple answer as to whether something is right or wrong as ethical issues tend to be multi-faceted. Nevertheless, according to Chan (2001), applied ethics is not subjective as any decision taken about a moral problem should be based on reasoning and require justification.

Ethics can also be understood as a set of standards which people use to guide them in their actions and in making decisions that they think are morally right. Such standards are made up of a collection of ethical principles. These are expressions of agreed values (or “rules of thumb”) which serve to guide people's actions in order to achieve the best possible ethical outcome, thereby encouraging people to consider the broader context and respect other people rather than being preoccupied with their own interests (State of Victoria, 2006).

## **2.2 Applying ethics to AT**

Different forms of technology are used every day which can make our lives easier or more enjoyable (e.g. espresso coffee makers, machines to bake bread and remote controls for the television or garage doors, to name but a few). However, with the exception of closed circuit TV in public places, this rarely poses ethical dilemmas as people are free to choose whether they want to use such technology in their own private domain based on the information available to them. On the other hand, it could be argued that this is a rather simplistic perspective and one could ask to what extent we really are free in relation to technology. Can we, for example, afford not to engage in the world of Internet, email, GSM communication etc?

In the case of children, certain ethical issues may arise but in most cases responsibility for decision-making is given to adults. In the case of dementia, the people using the technology are not necessarily able to fully understand the implications and may not have the capacity to give full consent, yet its use may be beneficial, enabling them to accomplish tasks that they would otherwise be unable to manage. Although the use of AT may sometimes create ethical dilemmas, often its use simply draws attention to ethical dilemmas which were already present but largely ignored or not clearly defined (Marshall, 2000).



Niemeijer et al. (2010) suggest that it would be wrong to consider AT as “morally neutral” because some devices and systems include characteristics which affect the rights of those using them and cannot be removed as they are “substantially rooted in the conception of the application” (Casas et al., 2006). The way that AT can be used is often dependent on decisions made during the design phase (Kubitschke et al., 2009). In the context of residential care, Niemeijer et al. (2010) point out that debates over the ethical issues linked to the use of AT tend to focus on the moral acceptability of the effects of its use rather than on its use per se with conflict often arising when the interests of institutions do not correspond with those of the residents.

Although it may sometimes be possible to choose whether or not to use a particular device and to try to consider the ethical issues linked to that choice, Hertogh (2010) argues it is perhaps somewhat naïve to think that in general people are free to choose whether or not to use technology and to use it in ways that are morally more or less acceptable. Indeed, people’s realities are in principle inextricably bound to the use of technology. It is part of our “condition humaine.” Consequently, the ethical question is not so much about what application of technology we want or do not want, but rather how technology shapes our world, our values and ourselves, and how we can best guide its inescapable role in our lives in a morally viable way. This question concerns all human beings, not just people with dementia (Hertogh, 2010).

People are not always aware of the ethical issues linked to the use of AT and it is likely that most act in good faith, trying to do what they feel is best for the person with dementia and bearing in mind his/her wishes. A description of different kinds of ethical issues which could be relevant to the use of AT would therefore be useful along with advice on how to act in the most ethical manner. Unfortunately, standard solutions or recipes for ethically sound behaviour cannot be provided as every situation is different as are the people involved. Often, acting in an ethical manner requires the assessment of the situation, people and possibilities as well as a consideration and in some cases balancing of various ethical principles in order to be able to decide on the best course of action for the person with dementia.

In the ethics section of the Alzheimer Europe website, ethical issues are discussed in detail. A brief description of some of the main ethical principles will be presented here.

### **2.3 A few ethical principles**

There are several ethical principles which are frequently mentioned in the context of healthcare and ethics. Perhaps the most well-known are those described in the Belmont Report of 1979, namely autonomy, beneficence and justice, to which Childress and Beauchamp (2001) added non-maleficence. Others include solidarity, dignity and integrity to name but a few.

Some ethicists strongly believe in the necessity of developing a hierarchy of ethical principles but others point out that there are cultural differences in the importance given to various principles and that a range of factors come into play when considering which principles are to be given priority in any specific situation (e.g. based on the people involved, their lived experiences and the severity of the disease). Moreover, in some cases, the respect of certain ethical principles may be interdependent. For example, autonomy, which is considered extremely important in the Western world, nevertheless makes no sense in the absence of other principles such as dignity and equity. Sometimes, part of dealing with ethical dilemmas involves trying to find the right balance between competing, but equally important ethical principles such as autonomy and beneficence. Sometimes, striving to respect an ethical principle for one person, may result in failure to respect an ethical principle for another person (e.g. giving one person the freedom to decide where he/she would like to walk may result in an intrusion into the privacy of another person, especially in community living arrangements). The following ethical principles are therefore not presented in any order of importance:

- autonomy
- beneficence and non-maleficence
- (respecting ) dignity and personhood
- (respecting) integrity
- privacy
- justice/equity (fair distribution of resources)
- (recognising) solidarity and dependency
- parentalism and paternalism
- (recognising) vulnerability

### **2.3.1 Autonomy**

Autonomy is traditionally considered as being linked to self-determination and exercising choice. For this reason, consent (which is discussed in detail in Part 3) is often central to debates about autonomy. As people with dementia experience a gradual deterioration of their cognitive capacities, their ability to make autonomous decisions is jeopardised but in many situations they can still contribute towards decision making. This is reflected in the second of the two main aspects of respect for autonomy identified by Beauchamps and Childress (2001):

1. Autonomous actions should not be subjected to controlling constraints by others
2. Respectful treatment in disclosing information, probing for and ensuring understanding and voluntariness, and fostering autonomous decision-making.

However, the Danish philosophers Rendtorff and Kemp (2000) describe 5 main meanings of autonomy which are as follows:

1. The capacity for the creation of ideas and goals for life.
2. The capacity for moral insight.
3. The capacity for “self-legislation” and privacy.
4. The capacity for rational decision and action without coercion.
5. The capacity for giving informed consent to medical experiments.

(Source: Ebbesen and Pedersen, 2008, p. 4)

The description of autonomy by Rendtorff and Kemp is quite capacity based, which might seem to not apply greatly to many people with dementia, but the authors also suggest that for certain groups of people (including people with dementia), the main emphasis should not be solely on autonomy but also on supplementary principles such as respect for dignity, integrity and vulnerability (please see below for further details) (Ebbesen and Pederson, 2008).

The capacity-based approach to autonomy, with its emphasis on rationality and being free to choose, has been challenged by Agich (2003). He draws attention to the paradoxical conjunction between autonomy and the long-term care of people with illness or disability:

*“Individuals need long-term care because they suffer illnesses and incapacities that compromise their ability to function independently or to choose rationally. Yet the standard concept of autonomy in bioethics stresses the ideals of independence and rational free choice, ideals that appear ephemeral in the face of the wide range of impairments that cause individuals to need long-term care.” (Agich, 2003, p.1)*

Agich emphasizes the necessity to consider the symbolic meanings of both autonomy and long-term care which are socially constructed and hence culturally determined. With regard to autonomy, he draws attention to associations between autonomy and self-reliance, personal preference and self assertion, adding that in societies where particular importance is given to the concept of autonomy, being dependent may be regarded negatively or as a defect and people who are dependent on others as having less value.

For Agich, actions and decisions are embedded in the habits and rituals of daily life and people act and decide within a complex web of interactions and relationships. Being autonomous therefore involves acting in the midst of all this and not in a kind of abstract bubble or vacuum. His perception of autonomy rejects the notion of a gradual development towards the status of autonomous being and of the need to preserve this, arguing instead that people are never really “finished” but always in the process of development and of dependency on each other for such development within a social context. For people who are dependent on others, or faced with obstacles due to ill-

ness or disability, autonomy may be expressed through attempts to adapt and cope irrespective of whether reasons for actions or choice can be rationally explained.

### 2.3.2 Beneficence and non-maleficence

Respecting the principle of beneficence involves trying to do what is best for someone, whereas respecting the principle of non-maleficence involves avoiding doing something that might cause them harm. The two principles are often mentioned together as in many cases, respecting one goes hand in hand with respecting the other.

Frankena (1973), who combined the two principles under the term beneficence, described four main goals:

1. One ought not to inflict evil or harm (what is bad).
2. One ought to prevent evil or harm.
3. One ought to remove evil and
4. One ought to do or promote good.

(Frankena, quoted in Dawkins, 1998, p.10)

Determining what is good for a person with dementia or “in their best interests” is not necessarily an easy task for three main reasons:

1. Personal preferences, views and value judgements of those making decisions on behalf of a person with dementia can easily slip into the decision-making process.
2. The preferences and feelings of the person with dementia about various issues may have changed since the onset of the disease. Proxy decision makers may be unaware of this and the person with dementia may be unable to communicate this to them.
3. In group settings, such as day care centres, hospitals or nursing homes, something that contributes to one person’s wellbeing may well be detrimental to that of others, or even lead to actual harm.

Considering what is best might involve an assessment of the balance between the extent and duration of positive experiences with that of negative experiences (Griffin, 1986) or a more objective consideration of what influences happiness, either positively or negatively (Finnis, 1980). The Nuffield Council of Bioethics (2009) considers cognitive dysfunction an important objective factor negatively affecting wellbeing. AT can therefore play an important role in enhancing wellbeing, thereby respecting the principle of beneficence.

With regard to the principle of non-maleficence, even if the use of AT would be somewhat unpleasant or lead to the non-respect of other ethical principles, not using AT might in certain situations be too risky (e.g. perhaps leading to accidents or neglect). Consequently, respecting beneficence and non-maleficence involves answering a few questions such as: Whose best interests? Who decides and assesses best interests? How

is this done? Can such assessments be made for groups of people? How can the two principles be balanced?

### 2.3.3 Dignity and personhood

Respecting the dignity of people with dementia is essential for their wellbeing, for the maintenance of their relationships with other people in their entourage and of a positive care relationship. It is also recognised as a fundamental human right which is anchored in several national, European and international texts (please see Annex 1).

Sometimes, people find it easier to identify failure to respect dignity than to define what dignity is. Examples of failure to respect a person's dignity might include not treating someone with respect, belittling, ridiculing or humiliating them, torture, ignoring or insufficiently acknowledging someone, seeing them as a member of a group rather than as a unique individual, and/or physically or mentally transgressing their personal space (Holmerová et al., 2007; Jacobson, 2007; Mann quoted in Horton, 2004). The principle of dignity is therefore closely related to those of personhood, privacy and respect.

Nordenfelt (2002) identifies four types of dignity:

1. "Menschenwürde"
2. The dignity of merit
3. The dignity of moral stature
4. The dignity of identity

"Menschenwürde" is the dignity that is inherent in being a human being. This is sometimes but not necessarily linked to spiritual beliefs. In German, this is reflected in the term "Menschenwürde" which reflects the undeniable value of human beings regardless of their social, mental or physical properties (Tadd, 2003). Another term that is often used is "basic dignity". People have the same degree of "Menschenwürde" throughout their whole lives and it is something that cannot be taken away from a person (Nordenfelt, 2002). It only applies to living people though.

The dignity of merit applies to people who are considered as having achieved excellence or distinction such as a high rank. This may be formally bestowed on a person or informally achieved by artists, athletes or scientists but nevertheless acknowledged and respected. This kind of dignity can be acquired and lost.

The third type of dignity, that of dignity of moral stature, is linked to self-respect and dignified conduct, as well as respecting other people's rights. This type of dignity is not linked to any right due to one's acts as if one's acts resulted in rights or privileges, the moral value of the act would be considered as less.

The dignity of identity is described as the kind of dignity that people attach to themselves as integrated and autonomous people who have their own history, future and relationships with other people. This type of dignity can be shattered by other people. There is a link to a person's perceived value and worthiness that is reflected back in the context of interaction. It can therefore be considered as an attribute that can be subjectively felt but also something which can be denied, ignored, withheld and violated. Although informal and professional carers may understand that people with dementia may sometimes unintentionally violate social norms, certain reactions (e.g. of disgust, disapproval or disdain) may inevitably be expressed (Seman, 2007). If detected by the person with dementia, his/her sense of dignity may be affected. This does not mean to say that all behaviour by people with dementia which challenges social norms is unintentional as it may actually be a form of communication, legitimate self expression or an appropriate response depending on the circumstances.

According to Seman (2007), the socialization of infants and children leads to an association between the acquisition of maturity and certain behaviours, including self-control (e.g. of bodily functions and emotional expression), with certain behaviours being reprimanded, criticized or leading to exclusion. This, combined with the general assumption that behaviour is intentional and fully controllable, may lead to negative reactions towards people who fail to meet social expectations or violate social rules, as well as self-criticism and shame from those concerned for whom such expectations are also deeply engrained.

Nordenfelt (2002) draws attention to illness, impairment, disability and old age which can rob a person of their dignity of identity. He highlights the often irreversible disablement, the knowledge of its permanent nature and the awareness that the person's identity is forever drastically changed, his/her privacy violated and dependency on others inevitable (hence a perceived loss of autonomy).

Finally, treating people in an undignified way or leaving them in what might generally be considered an undignified state (regardless of whether they are actually disturbed by this) has implications for respect of their dignity, integrity and personhood. Nordenfelt (2002) explains that the dignity of identity is also objective because it can be violated even in cases where a person is not aware of the violation or even no longer alive. This might involve leaving a person naked in the presence of others or treating a dead body with disrespect.

Personhood, like dignity, has a fundamental inherent character as well as a socially constructed and maintained character. Consequently, perceived lack of dignity may result in people being seen as objects which could jeopardise the likelihood of authentic interaction which is essential for the respect and preservation of their personhood.

Buber (1970) identified two different ways that people relate to one another, which are also of relevance to the maintenance of personhood in people with dementia. 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 involves meeting the other person in a genuine human exchange. People with dementia may eventually lose the capacity to create and encourage a genuine human exchange. If, in addition, they have become an object in the eyes of other people, their personhood may be jeopardised (i.e. personhood in the sense of social acknowledgement of their value as unique human beings).

#### 2.3.4 Integrity

Josephson (2010) emphasises the origin of the word integrity which comes from the same Latin root as “integer” meaning whole number. This suggests something that is undivided and whole.

According to the Danish philosophers, Rendtorff and Kemp (2000) integrity has two moral dimensions. The first consists of a created and narrated coherence of life, in the form of a coherent and complete life story, which should not be violated. The second consists of a personal sphere for experience, creativity and personal self-determination (Ebbesen and Pedersen, 2008). Some people with dementia may have difficulty communicating their life story and protecting or promoting their personal sphere. Some effort on the part of carers may therefore be necessary to ensure that the integrity of people with dementia is respected.

Integrity might also be relevant for people faced with ethical decisions, highlighting the need to be consistent and constant with regard to their own principles and subsequent behaviour, engaging in careful consideration so as to avoid being led by events and circumstances (Josephson, 2010).

#### 2.3.5 Privacy

Privacy refers to the ability of people or groups to seclude themselves or information about themselves from others, thus permitting them to reveal themselves and information about themselves when they choose to do so (Wikipedia, 2010). Different cultures and different individuals have different limits and beliefs about privacy (i.e. about which aspects of themselves or information they would like to keep to themselves and which they are willing to share or make available to others). This also includes the physical/geographical boundaries of their private sphere. In some countries, the term “privacy” is not easily translated, with some using a complex description and others borrowing the English term (Anderman and Rogers, 2003).

One of the earliest legal definitions of privacy was provided by Warren and Brandeis in their article “The Right to Privacy” which was printed in the Harvard Law Review of 1890. They described it as the right to be let alone which together with the right to liberty was part of the right to enjoy life (University of Louisville, 2010).

Niemeijer and Hertogh (2009) propose four types of privacy, namely informational privacy (e.g. sensitive or personal information), physical privacy (e.g. one’s personal space), attentional privacy (e.g. unsolicited mail or telephone calls) and decisional privacy (e.g.

being able to choose a particular action without interference from the state). They suggest that with medical ethics the emphasis tends to be on informational privacy but that in the case of people with dementia for whom no direct (acute) recovery is likely, the emphasis is more on physical privacy (i.e. the right to be let alone). On the other hand, they draw attention to the risk of taking this to the extreme which could lead to neglect and emphasize the need to balance the right to physical privacy with the respect for various needs such as intimacy and feelings of security.

### **2.3.6 Justice/equity (fair distribution of resources)**

In healthcare ethics, the principle of justice 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). With reference to AT, justice would be linked to issues of fairness and equal entitlement and access to various devices and systems.

People with dementia are generally elderly and most eventually experience difficulties with comprehension, language and memory. Consequently, they are not ideally placed to find out about the different types of AT that are available and to demand access to it. Such difficulties are the very reason why they might benefit from many forms of AT. People with dementia who are on a low income, who are not fluent in the national language of the country and who come from other stigmatized groups may be at an even greater disadvantage.

The principle of justice also applies to the fair distribution of goods and services between different groups in society (e.g. people with learning disabilities, people with cancer, people with physical disabilities and people with mental disorders) who may unfortunately find themselves competing for their share in the limited resources available for health and social care. People with dementia should have equal access to assistive technology if and when needed. However, a diagnosis of dementia is sometimes used to deny people with dementia access to some forms of care (WHO, 2002b). Also, in some countries, as dementia is not recognised as a disability and AT is often associated solely with physical disability, they do not have equal access. It is possible that the stigma of mental illness, of dementia and associated with age (i.e. ageism) contributes towards this failure to respect the principle of justice with regard to people with dementia.

Some forms of AT are not yet mass produced and consequently fairly expensive and not readily available. Prices can also differ depending on the type of device or system needed. A study into safety and monitoring devices carried out recently in Finland tested various types of technology which ranged in price from EUR 30 to EUR 2,100 per person with an average price of EUR 600 per person (Riikonen et al., 2010). Certain devices would clearly be too expensive for some people if they had to cover the full cost themselves and one could question whether such expenditure by the State would be justifiable on the grounds of distributive justice. However, the researchers also point out that the average cost of residential care for a person with dementia in Finland comes to about EUR 3000



per month and also that the results of their study suggest that AT may delay entry into residential care.

As people are not all equal in the first place (in certain respects), justice must be more than just treating people equally and it may be unjust to treat unequals equally (Gillon, 1994). However, justice may be difficult to achieve. In some countries where the availability of AT is not yet widespread, access to it is restricted to people on a very low income which means that those who do not fall into this category, but who nevertheless could not afford it themselves, are denied access. People with dementia and carers with limited resources may have no choice about the use or non-use of AT if it is the only option they can afford. Access may also be granted to people whose condition is most severe when in fact people in the earlier stages might benefit most from it.

Perry, Beyer and Holm (2009) distinguish between people's needs and wishes for AT, pointing out that respecting the principle of justice requires that the needs of the individual be balanced with those of the wider community. The principle of justice can also be considered in relation to carers in that the question of fairness arises in decisions linked to the distribution of burden (or stated more positively the responsibility for care) between the State and informal carers (Kubitschke et al., 2009).

A feminist perspective on justice highlights the importance of relationships and care and in particular the need to ensure fairness/equality between men and women. If responsibility for care is given to family carers, this often means that it is given to women who are simply expected to provide such care and often cost free. In the ENABLE project, particular attention was paid to issues surrounding the recognition, value and rights of carers (most of whom were women) as well as to the involvement of paid homecare workers who also tend to be women and are often low paid and have low levels of education (ENABLE, 2004).

### **2.3.7 Solidarity and dependency**

Dependency is often perceived as being linked to stages or particular situations in a person's life such as infancy, disability, illness and old age but in fact people are all dependent on each other in numerous ways throughout the whole course of their lives (e.g. for food, clothing and services but also for more emotional, social and psychological needs). Agich (2003) suggests that as dependency is not limited to old age and frailty, it should not be expressed as a consequence of such. Rather dependency experienced by some but not all elderly people (or in this case, by particular people with dementia) should be considered as the unique way that it is manifested and experienced by the people concerned.

Interdependence 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. Such a response can be described as solidarity. The principle of solidarity is closely linked to that of justice/equity as it covers the issue of cooperation between people. It recognises that some groups of people are vulnerable and may need support

i.e. they may be dependent on others for their physical, emotional or practical needs. In some cases, solidarity (especially in connection to social and healthcare) is organised officially by the State and may take the form of obligatory social charges or healthcare fund contributions.

Such interdependency has been described as being based on social contracts between “rough equals” but this has been criticised due to its emphasis on reciprocal bargaining and self-regarding interests. Nussbaum (2001), for example, draws attention to asymmetrical forms of dependency (e.g. linked to the care of infants, extremely old people and people with severe illnesses or long-term severe disability) and points out that certain groups (often those who are most vulnerable) are excluded from this bargaining process.

Silvers and Francis (2005) take a different approach to understanding interdependence and solidarity. They emphasize the importance of trust and believe that “mutual comprehension can be induced by shared feelings or by common reasons” and that this does not always have to necessitate negotiation. They also suggest that self-interest (e.g. in providing for one’s own possible future needs) may contribute towards acts of solidarity.

Whether solidarity is based on self-interests or other-interests, measures should be taken to ensure that vulnerable groups are involved to the greatest extent possible in the kind of support provided and the way that it can be implemented.

### **2.3.8 Parentalism and paternalism**

Being dependent on others to make decisions on one’s behalf due to various forms of incapacity sometimes results in paternalistic attitudes or behaviour (e.g. reflecting the presumption that “we know what is best for you”), resulting in a person being treated as a child and their autonomy not respected.

However, Landau et al. (2010) suggest that fears of paternalism may lead to some professionals erring on the side of autonomy at the expense of advising patients about particular courses of action.

Hertogh (2010) states that 20 years of empirical research in ethics has shown that the move from paternalism to autonomy might have gone too far. He reports widespread support for the more realistic strategy of shared decision-making, involving people with dementia, their carers and healthcare professionals in a collaborative effort to define mutually acceptable goals of care. This strategy acknowledges that our autonomy is always relational and embedded in a web of mutual interdependencies, which has implications for the issue of consent. This does not, however, reduce the need to always seek the consent or assent of the person with dementia.

Recognising that a person may nevertheless have difficulties making decisions but also have a right to lead an autonomous life insofar as this is possible, some authors prefer to use the term “parentalism”, not as a means to avoid sexist terminology, but rather to

emphasize the aspect of parenting which coordinates assistance and the encouragement of whatever level of self-expression or autonomy is possible for the individual. This has been described as a “situation in which an affectively concerned caregiver strives to enhance the wellbeing, including the autonomy, of another dependent individual” (Agich, 2003, p.48). Agich (2003) describes parentalism as something that is rooted in the basic response to the needy other that relationships based on the interconnectedness of all human beings engenders. As such it is very much linked to the concept of interdependency.

### **2.3.9 Vulnerability**

Vulnerability is a term often used when referring to specific groups of people who, for a variety of reasons, need extra care or support (e.g. infants, pregnant women, disabled people and people with dementia). However, Rendtorff and Kemp (2000) draw attention to the temporal and finite quality of all human life which indicates that the human condition is fragile. R.D. Laing described this with a touch more humour, stating, “Life is a sexually transmitted disease and the fatality rate is one hundred percent.” Acceptance of the vulnerability of humans is therefore essential for the development of moral behaviour towards other humans, for providing support and care when needed, and expressing empathy towards them.

## **2.4 A wider framework - quality of life, personalism and relationships**

### **2.4.1 Quality of life**

Some ethical principles are closely linked to quality of life. In their assessment of the extent to which technical support might contribute towards the quality of life of people with dementia, Heeg et al. (2005) therefore also assessed the extent to which various devices and systems affected autonomy, safety, privacy and dignity amongst other criteria. Beauchamp and Childress (2001) point out that the “best interests” standard frequently used when making decisions about beneficence and maleficence is inescapably a quality of life criterion. They also suggest that quality of life considerations should be based on whether a particular intervention is beneficial to the person concerned rather than whether that person’s life is beneficial to him/her. They were referring to medical interventions but this could equally apply to decisions about the use of AT.

A framework was recently developed by Banerjee et al. (2010) for the systematic assessment of the quality of life impacts of services and policies for people with dementia and their informal carers based on a series of six structured discussions with professionals, people with dementia and carers attending international dementia conferences. Whilst the findings cannot be generalised, this study provides some insight into what people might mean by quality of life in the context of services for people with dementia.

312 individual contributions of text were analysed using qualitative thematic analysis. Of the ten most commonly used words, the highest score was for choice (mentioned 145 times) followed by time (139), love (120), spirituality (80), communication (69), education

(54), respect (53), safety (49), touch (43) and fun (43). The analysis of the data resulted in the emergence of 8 domains. The one which represented the largest number of chunks of coded text was “choice and personhood” (including empowerment, respect, identity and spirituality), issues which are related to some of the ethical principles which have been discussed in this section.

#### **2.4.2 Personalism**

Baldwin (2008) nevertheless criticises Beauchamp and Childress’s approach (which he classes as “principlism”) for failing to acknowledge personhood and for its focus on decision-making. In addition, Petrini and Gainotti (2008) highlight the lack of information about what precisely is “good” and “just”. Drawing on the work of Buber (1970), Levinas (1961) and Schotsmans (1999), Baldwin (2008) proposes “personalism” as an ethical framework, which focuses on “the uniqueness of each person, the relational and intersubjective nature of persons and the notion of participation in the wider society through communication and solidarity” (Baldwin, 2008, p. 107). The primary ethical principle of personalism is perhaps that all human beings deserve respect but personalism also requires positive attitudes in addition to the simple passive avoidance of negative actions and behaviour (Petrini and Gainotti, 2008).

#### **2.4.3 Relationships**

Relationships must be taken into consideration when taking ethical decisions regarding the use of AT for people with dementia, particularly when AT is being implemented in the home as this may be the home of several people. Consequently, the privacy, dignity, autonomy and possible consequences for everyone concerned are of importance and everyone’s consent should be obtained. Where transformations of the home are necessary, it could also be the case that the home belongs to other members of the household and not to the person with dementia.

Often the use of AT is dependent on the cooperation of other people so if they are not happy about its use, it will often not be used. The issue concerning control of the AT (i.e. who can disable or switch it off) may also affect and even disrupt existing power relations between members of a household.

### **2.5 Legislation**

There is a close relationship between ethics and legislation in that ethical principles underlie many laws and in addition, laws may be passed in various domains to ensure that various ethical principles are respected. On the other hand, there is sometimes a difference in time between acceptance of what is acceptable or desired in a specific situation or domain and there being a law to ensure that this happens.

Various ethical principles can be found in the constitutions of several countries as well as in other national laws, and a few European and international conventions such as the United National Universal Declaration of Human Rights, the European Convention on

Human Rights and the European Convention on Human Rights and Biomedicine. Please see Annex 1 for a few examples. The main principles of relevance to the use of AT in the above-mentioned conventions are dignity, privacy, liberty, self-determination and non-discrimination. The Convention on Human Rights and Biomedicine addresses in detail the issue of consent in the case of people lacking capacity. The various issues covered can also be considered as being linked to the ethical principles of beneficence, maleficence and autonomy.

### 2.5.1 Privacy and dignity

In the American legal system, the concept of privacy has been defined as “the right to be let alone” with further categorisation relating to physical privacy, informational privacy and decisional privacy (Bharucha et al., 2006). The European data protection directive is very much concerned with confidentiality and respecting privacy but seems to focus on informational privacy. In national conventions and certain European conventions, dignity mainly takes on the form of respect for and lack of interference in private and family life.

Privacy and dignity are also mentioned in some charters which are influential at national level and whilst not actually laws, they may have a considerable impact on the provision of health or care services. For example, dignity and privacy are two of the six key principles outlined in Scotland’s National Care Standards (the others being choice, safety, realising potential, and equality and diversity. A care commission was set up in April 2002 under the Regulation of Care (Scotland) Act 2001 to regulate all adult, child and independent healthcare services in Scotland and it is the duty of the care commission to ensure that all care service providers meet the standards set by the Scottish government (Care Information Scotland, 2010).

Similarly, in Germany there is a Charter of Rights for people in need of long-term care and assistance which was published by the German Federal Ministry of Family Affairs, Senior Citizens, Family and Youth in 2007. In the preamble, reference is made to the unqualified entitlement to respect for the dignity and uniqueness of all human beings and the special responsibility of the state and society to protect the human dignity of those in need of long-term care and assistance.

### 2.5.2 Data Protection Laws

An issue which frequently arises in connection with the use of surveillance and monitoring devices and systems is data protection. In 1995 the Data Protection Directive (Directive 95/46/EC on the protection of individuals with regard to the processing of personal data and on the free movement of such data) was implemented by the European Commission. Whilst it was not legally binding for citizens, it obliged Member States of the European Union to enact their own data protection laws. According to the Justice and Home Affairs’ website of the European Union, all Member States have done so, as well as Liechtenstein and Norway (information is missing for Iceland and Switzerland) (please see: [http://ec.europa.eu/justice\\_home/fsj/privacy/law/implementation\\_en.htm#belgium](http://ec.europa.eu/justice_home/fsj/privacy/law/implementation_en.htm#belgium)).

The directive covers the processing of personal data by automated or manual means. Personal data is understood as meaning any information relating to an identified or identifiable natural person. In the context of AT, this might include written records or summaries of a person's movements linked to their name, address, medical condition and prognosis etc. The situation with regard to visual information is quite complicated. We did not find a European resolution or regulation etc. which explicitly claimed that one's image is personal data. However, the Hungarian Data Protection law explicitly states that a person's image is personal data. Moreover, in the definition of personal data (official directive 95/46/EC on the protection of individuals with regard to the processing of personal data and on the free movement of such data) the keyword is identifying (and identified, identifiable etc.). From a good quality video recording<sup>3</sup> anybody can be identified. Hungarian data protection experts thus they had no doubt about this being personal data. Also some guidelines of the European Data Protection Supervisor suggest the same when promoting data protection principles for CCTV (closed-circuit television) devices. Based on the findings of a number of German studies, there seem to be two positions. The first considers that any measure of personal data - even if it is only live video surveillance - involves handling personal data<sup>4</sup>. Therefore it is an intrusion into a person's privacy and consequently, has to be in line with constitutional principles and legal documents. The second takes the stance that handling personal data only starts when live video surveillance is accompanied by other actions, such as storage<sup>5</sup>. We therefore conclude that video recording can be considered as involving the handling of person data but that there may be differences between countries with regard to live video recordings (Kapronczay, 2010).

Indeed, the purpose of data protection is to protect people's right to privacy. Thus, even if according to the law of a given country live video recordings are not considered as the handling of personal data, they are nevertheless an intrusion into people's privacy. Consequently, alternative solutions should be sought and the wishes of the person with dementia certainly taken into account.

Under the European Directive, three main conditions must be met if any form of personal data is to be processed, namely transparency, legitimate purpose and proportionality. Transparency means that the person whose personal data is being processed is aware of this and has given consent. The person who is controlling the data must have given his/her name and address and stated why s/he is processing the data. Legitimate purpose means that the data must have been processed for specific and legitimate purposes. It cannot be further processed in ways that are incompatible with those for which it was initially collected (e.g. used to plan better care but later disclosed to commercial AT providers). Finally, the principle of proportionality means that the processing of personal data must not be disproportionate to the need. It must also be relevant and adequate. For example, 24-hour video surveillance and recording of a person's every movement to determine whether s/he takes his/her medication at the right time would not be proportionate to need as another method could be devised to ensure the timely taking of medication.

3 We are using "video recording" as a general term to cover any type of recording of a person's image regardless of whether the recorded image is stored, live, digital, on a film reel, with or without sound etc.

4 Michael Dorderer: Verfassungsfragen der „Sicherheit durch Null-Toleranz“, NVwZ. 2001/2., 131

5 Königshofen, Neue datenschutzrechtliche Regelungen zur Videoüberwachung, RDV, 2001/5., 222

### 2.5.3 Disability

In some countries people with disabilities have certain rights which might include access to or assistance financing AT. The United Nations Convention on the Rights of Persons with Disabilities and its Optional Protocol, which came into force in 2008, has been signed by all member states of the European Union as well as Iceland, Norway and Turkey and ratified by 16 member states as well as Turkey. However, dementia is not always officially recognised as being a disability with the result that laws and regulations governing access rights are open to interpretation. On the other hand, in some countries, dementia (or more specifically, Alzheimer's disease) is legally recognised as a disability, thereby facilitating access for people with dementia to appropriate support, which might include AT. Alzheimer Europe asked legal experts in some of its member associations whether dementia or Alzheimer's disease was legally defined as a disability in their countries. The following responses were received.

*Table 1: Responses from legal experts concerning legal definition of dementia as a disability*

Response	Country	Comments
NO	Belgium	
NO	Bulgaria	
NO	Czech Rep.	
NO	Finland	
NO	Greece	
NO	Luxembourg	
NO	Poland	
NO	Switzerland	To the best of our knowledge, nothing at federal level.
YES	Cyprus	The Law on Public Assistance
YES	Denmark	Considered as illnesses which in time can result in legal disability
YES	Germany	
YES	Romania	Order No. 90 of 9 August 2002
YES	Scotland	Dementia is legally defined as a mental disorder under the Adults with Incapacity (Scotland) Act 2000 and the Mental Health (Care and Treatment) (Scotland) Act 2003. Mental disorder is legally defined as a disability.

Nevertheless, official recognition of dementia or Alzheimer's disease as a disability does not always ensure access to services and support (and vice versa).

In Finland, for example, dementia is mentioned in some government proposals such as the Act on Continuing Powers of Attorney but the fact that it is not mentioned in the Disability Act, which is interpreted as applying only to physical disabilities, means that people with dementia are not entitled to disability benefits. This is further complicated by the tendency, not just in Finland, to consider dementia as being part of “normal ageing” (Mäki-Petäjä, 2010).

In Romania, on the other hand, dementia and Alzheimer’s disease are legally defined as disabilities under Order No. 90 of the 9 August 2002 which would normally make people with dementia, or more specifically with Alzheimer’s disease, eligible for certain benefits but as methodological norms have not yet been developed, such rights are not necessarily translated into practice (Dobranici, 2010).

Finally, in Poland, whilst dementia or Alzheimer’s disease are not officially recognised as a disability, they would be considered as disabilities under The Charter of Rights of Persons with Disabilities (Resolution of the Polish Sejm /Parliament of 1 August 1997) where people with disabilities are defined as “those whose physical, mental and intellectual abilities, permanently or periodically, make it difficult or impossible for them to run everyday activities, to study or work as well as to fulfil social roles, in accordance with legal and customary norms.”







***Ethical issues linked  
to the use of specific  
forms of AT***

### 3 *Ethical issues linked to the use of specific forms of AT*

In this section, we will look at the various ethical issues raised by the use of AT. For the sake of organisation, AT systems and devices will be divided into four main categories, namely, the use of AT:

1. for leisure and social inclusion.
2. in the form of socially assistive robotics
3. to enhance safety and wellbeing in the home
4. for memory and mobility
5. for surveillance, safety and monitoring

However, there will be some overlap between the sections as this is clearly an arbitrary categorisation and different types of AT do not have such distinct boundaries. As the issue of consent covers the use of every kind of AT this will be discussed first.

#### 3.1 **Respecting autonomy – the issue of consent**

##### 3.1.1 **Obtaining informed consent or assent**

Difficulties obtaining the informed consent of people with dementia for the use of AT are quite similar to those linked to consent to medical treatment. Care must be taken to ensure that the person with dementia understands the information that is given, can retain it long enough to make a decision and can express his/her decision. This may sometimes be difficult due to the technical aspects of some devices (Fisk, 1997).

Consent must amount to more than agreement to the use of AT without understanding its function (e.g. consenting to wear a bracelet without realizing that it enables other people to monitor one's whereabouts). Certain types of tracking device cannot be easily discarded which means that once they have been put on, the person with dementia no longer has the freedom to take them off, even if they are cumbersome or s/he later objects to their use. One system requires two hands to take the bracelet off (Miskelly, 2004). This puts people using such devices in a vulnerable position in which they have no power and may feel humiliated and trapped.

Different ways of presenting the information can be used and measures can be taken to check whether the person has really understood what is at stake and the consequences for him/her. There may be a tendency to conclude too hastily that the person does not have the capacity to consent and to ask carers instead. However, even in the case of incapacity to consent to the use of a particular form of AT, the person with dementia should be involved in the decision making to the greatest extent possible.

The capacity to consent is likely to deteriorate over time and in some cases may fluctuate from day to day or at different times of the day (Jacques and Jackson, 2000). A person may therefore consent to the installation of surveillance equipment but later not be aware that s/he is being monitored or able to reaffirm or withhold consent. Yet his/her desire for privacy may change as the disease progresses. It might be possible to obtain his/her views on the matter if the necessary time and effort were taken but the de-installation of the equipment might involve costs which the person with dementia would have to be able to consent to. For this reason, Essén (2008) emphasizes the importance of having built-in possibilities to exit such services.

People who are responsible for obtaining the informed consent of people with dementia for the use of AT devices or systems should have received training in relevant communication methods as otherwise it could not be said that such consent had really been sought. This would mean that the rights of people with dementia had not been respected (Martin et al., 2010).

### **3.1.2 Ensuring that consent is given freely**

It is important to obtain the person's free and informed consent before installing or using AT. In the case of movement monitoring, for example, a person may be willing to sacrifice a certain degree of privacy in return for the benefits that s/he believes the device will bring but consent must not be based on pressure (e.g. the person being told that otherwise her/his husband/wife will not be able to sleep) or presented as the only option (e.g. being told that otherwise there will be nobody to help in case of need, that the use of such devices is standard policy in a particular nursing home or that it is obligatory for insurance purposes).

Perry, Beyer and Holm (2009) draw attention to possible coercion which may be subtle and even unintentional, e.g. the fears of staff about the use of AT being passed on to the potential users. People with dementia who are in hospital or residential care are in a vulnerable position in that they may fear retribution if they do not consent to the use of AT. Alternatively, they may be inclined to give a socially desirable response particularly if the person asking is perceived as having a higher status than them.

In the case of learning disabilities, it has been found that some people with learning disabilities have a tendency to acquiesce (i.e. respond positively irrespective of the question asked) and to select the last of two possible options given (i.e. if asked whether they would like tea or coffee, they would say "coffee" but if asked whether they would like coffee or tea, they would say "tea") (Sigelman et al., 1980 and 1982). It has been reported in connection with a person with dementia (Redfern et al., 2002) but it is not known whether this is common although it could at least apply to some people with dementia with learning disabilities.

Of course, it would be an over-simplification to portray people who are monitored, tracked or tagged as passive victims manipulated by care providers, as they have some-

thing to gain from this kind of AT such as a sense of feeling cared for and protected in the privacy of their own home (Essén, 2008).

### 3.1.3 When AT affects other people

The issue of consent is further complicated in group settings where one person's desire to use AT may infringe on another person's right to privacy or the other person may object to the use of a certain device or equipment (e.g. in the case of video surveillance of a shared room or of communal areas such as kitchens and lounges) (Bharucha et al., 2006; Perry et al., 2009). People sharing a room might also have different levels of capacity to consent, with some being able to decide themselves and others not.

Shinoda-Tagawa et al. (2004) have described the use of video surveillance as a means to investigate resident-to-resident violence. However, as almost 50% of violent acts reportedly occur in residents' private space, this raises issues linked to privacy and in the shared areas to obtaining the consent of all concerned, including visitors (Sifford and Bharucha, 2010).

Staff also have a right to privacy. When used as part of a research project, it has been suggested that care staff who object to video surveillance could be temporarily reassigned to another unit (Sifford and Bharucha, 2010) but clearly such a solution is likely to be unrealistic in the case of prolonged use of such surveillance. It is possible that the consent of staff to the use of surveillance equipment is not always requested, but in cases where they are informed in advance of its installation, it has been suggested that their continued employment may be considered as implied consent (Carlson, 2001; Bharucha et al., 2006). However, with high levels of unemployment in most countries, people may feel that they have less freedom to decide not to stay and as equipment is introduced into more and more establishments, this might even necessitate a change of profession, which for some people may seem impossible if they have specialised in that particular domain. Consequently, it could be argued that a certain degree of coercion is present in such implicit consent.

## 3.2 The use of AT for leisure and social inclusion

### 3.2.1 Communication and social interaction

Multimedia software can be used in a variety of ways to stimulate physical and cognitive capacities, and to increase social interaction or contact with the outside world. Computer-based activities, for example, may be either solitary or involve interaction with others. Some may be based on cognitive stimulation; others may provide a pleasant experience or be combined with physical exercise. Whilst elderly people of today are not generally as knowledgeable about computers as the younger generation, using computer technology may help bridge the gap between generations and provide a common interest or activity which can be shared with younger people, thereby promoting inter-generational social interaction and in some cases helping maintain family ties.

The use of various devices has also been shown to promote social interaction amongst residents in residential care. An example is the picture gramophone which was developed in Finland and tested in the ENABLE project in some residential care homes. This is an easy-to-use device which does not necessitate any knowledge of computers. By simply touching icons on a computer screen, people with dementia can listen to the songs of their choice and see the lyrics displayed on the screen. The results of the study showed that it created social interaction (with two to three people using it together), led to singing/humming and was an enjoyable activity (Topo et al, 2004). In a different study involving the use of touch-screen displays for photos, videos and music for reminiscence work, it was found that this approach gave people more control over the direction of the conversation which in turn resulted in more prolonged engagement in the conversations (Castellot-Lou et al., 2010).

Such devices could presumably also be used in people's homes. A possible drawback may be that some people who are not involved in the activity may overhear songs which they find annoying or which are associated with painful memories from the past.

The "window on the world", described by Orpwood et al. (2007), relays images from the outside onto a screen, which is located in the person's living environment. The images might be of people moving about outside, of visitors in a common room or of the garden (depending on where the camera is placed). This device might raise ethical and legal issues linked to obtaining consent or at least informing people that they are being filmed. Concerning people with dementia, this technology has the advantage of creating a link to the outside world as well as providing stimulation, perhaps creating opportunities for social interaction amongst viewers, but may also be enjoyable for people who are bored just sitting down all day with nothing to do. It might also be appreciated by people who are bedridden or have serious problems with mobility. It also has the advantage of being suitable for people who have great difficulty communicating but should not reduce efforts to maintain real human contact with them.

A drawback to such a device (and to the others mentioned in this sub-section) is that in communal settings, some people may find it annoying, disturbing or an intrusion into their personal worlds. Careful planning and attention to the location of such devices may help prevent other residents being disturbed.

Some forms of AT, such as video-telephoning, can be equally important in breaking the isolation of carers as that of people with dementia. It may also serve as a means of mutual support amongst carers or to help maintain communication between couples when one goes into residential care (Sävenstedt et al., 2003). Video-telephoning may also enable relatives and friends who are unable to visit as regularly as they would like to keep in touch with a person with dementia in residential care, reassure themselves that s/he is alright and perhaps reduce feelings of guilt about not visiting (Sävenstedt et al., 2003). In a study which set out to assess the level of satisfaction with such equipment, it was found that some carers received support from other carers during the bereavement

process following the death of the person with dementia during the study (Magnusson and Hanson, 2003). The researchers felt that it would have been unethical to withdraw the equipment at that time and they draw attention to the risk of people becoming dependent on equipment which is subsequently withdrawn.

### **3.2.2 Privacy**

Video-phoning, like monitoring for safety purposes, may be perceived as an invasion of a person's privacy. Whilst someone is sitting in front of the screen talking to someone, anyone who walks past may be captured on screen against their will or without their knowledge. In families with children and teenagers, it is unlikely that every one of them would have been asked to consent to the installation of such equipment. There may also be visitors who are unaware that their image is being recorded. Some people are very susceptible about their image and would be disturbed if they realised that they had been filmed in their pyjamas, without make-up, wearing curlers or having just woken up etc.

The person using the video-phone should also have a certain degree of privacy. For this reason, it would be good to have the video-phone in a separate room or private area but not all households have this option.

### **3.2.3 Restraint**

Having an open-line video-phone system, which is permanently switched on, opens up the possibility of professional carers or relatives using this system to ensure from a distance that the person with dementia remains in the home. This could be interpreted as a form of non-maleficence but it could also be considered as a form of restraint in that the person may feel compelled to comply (Magnusson and Hanson, 2003).

### **3.2.4 Dignity**

It could be argued that certain activities are inappropriate for elderly people and that encouraging people with dementia to participate is demeaning and fails to respect their dignity, particularly when it concerns activities that they would not, in the opinion of others, have done prior to having dementia. This is based on three assumptions: 1. that there are activities which are appropriate for certain age groups and others that are not 2. that people's likes and dislikes do not change over time, and 3. that if they do change, after a person has developed dementia, they should not be considered as valid. Each assumption could be challenged.

People with dementia are constantly adapting to new situations and the experience of having dementia may result in a different outlook on life and even changing interests. It would be a mistake to consider every change as being linked to damage to the brain (Kitwood, 1993). Possibilities to engage in activities may arise which were simply not previously envisaged but which nevertheless prove rewarding. Moreover, the social and leisure activities of elderly people have already changed considerably in the last few decades, perhaps due to older people being physically fitter, having fewer family and

professional responsibilities, greater purchasing power and better mobility than in the past (Föbker and Grotz, 2003).

Some concerns about dignity may be valid and care must be taken to ensure that people are not being pressurised to take part in activities which they personally find demeaning or of no interest. However, attention must also be paid to ensuring that a person's autonomy is respected and his/her current wishes respected. As Lawrence (2007, p.555) points out, "Caring transforms family relationships, and carers may fight to protect and preserve their own image of the person with dementia, with the risk of losing contact with his [sic] present needs and identity."

### **3.3 Socially assistive robotics**

Socially assistive robotics (SAR) is an area of AT which is still very much in its early stages, particularly for use with people with dementia. Most of the information in this section is taken from the writings of Sherry Turkle (2007) and Feil-Seifer, Skinner and Mataric (2007). Please see the references section for full details.

There are different kinds of SAR systems such as companion robots which provide a focus of attention (e.g. in the form of a soft toy/animal which responds to touch or sound), or non-contact assistive robots which provide support in social interaction with little or no physical contact. A companion robot that has received a lot of attention in the media recently is "Paro" the baby harp seal developed by Dr Takanori Shibata. The producers of this robot divide companion robots into four categories:

1. human-like
2. familiar animals such as dogs and cats
3. non-familiar animals such as seals, penguins and whales
4. new characters and artificial animals

and consider Paro as being in the third category (National Institute of Advanced Industrial Science and Technology (NIAST), 2010).

According to Feil-Seifer et al. (2007), the use of companion robots has led to reduced stress levels and increased social interaction amongst residents in nursing homes. Robots can also be given a kind of personality, e.g. serious or playful. This may affect how people with dementia react towards them and feel about them.

#### **3.3.1 Attachment**

SARs can have varying degrees of human-like appearance or qualities or with companion robots, varying degrees of similarity to living creatures. Turkle (2007) claims that this may create social side effects with ethical ramifications. A person may become attached to the robot but may have to share it with other people, the robot may break down or



the person may be moved to another unit or home and have to part with it. He/she may come to consider the robot as “real” and become disappointed by it. In an exploratory study into the psychological effects of domestic AT, Cesta et al. (2007) found a clear preference by elderly people for the “no-face” version of a prototype assistive robot and that the “no-face” version resulted in deeper psychological attachment.

The designer of Paro (the baby harp seal robot) experimented with companion robots representing animals with which people were more familiar such as cats. They found that the initial reaction was very positive but that people soon started to make comparisons between the robot and real cats and were soon disappointed that the robots did not feel the same or react the same as cats they had known. They did not tend to do this with the seal which is an animal that most people are not familiar with, but found it very cute and developed an emotional attachment to it (NIAST, 2010).

Evidence that attachment is not limited to lifelike creatures was provided by a study into children’s use of “Furbies” (please see image). The children had formed such close emotional bonds to their Furbies that when the creatures broke, most children did not want a brand new replacement but rather the old one mending or “cured” (Turkle, 2004). These findings cannot be generalised to people with dementia but provide useful insight into the human capacity to attach to inanimate objects.

### 3.3.2 Authentic interaction/reciprocity

Another concern linked to the use of SARs is their authenticity or rather lack of it. Some people may feel that there is something uncanny about a computer which seems to show concern or exhibit caring behaviour, whereas others might appreciate this or simply have no problems with it. In the 1970s a famous computer programme known as “Eliza” was developed which was capable of mirroring input and providing supportive feedback. For example, to the statement “My mother is making me angry,” the computer might respond “Tell me more about your family.” On the basis of observation of students interacting with Eliza, Turkle (2007) suggests that they were not pretending to be chatting with a human but actually enjoying talking to a machine. A more recent example is the Tamagotchi and similar devices/creatures which promote a desire to nurture and the illusion of reciprocation (Turkle, 2007). Some SARs can be programmed to make eye contact based on detection of where a voice is coming from. SARs are different to traditional teddy bears and dolls in that they are active, demand attention, require nurturing behaviour and/or react to the user’s behaviour.

The use of SARs by people with dementia is probably fairly limited at the moment. Ethical questions may nevertheless arise such as whether it is right to give SARs of this kind to people whose ability to interact with humans is declining, who might at some point be unable to understand that something is not “alive” and who may be feeling isolated. However, one could also argue that anything that makes a person feel cared for, wanted, of interest to someone/thing else and drawn into interaction can only be a good thing.

### **3.3.3 Privacy**

Although SARs are not human, programmed reactions towards the behaviour and movement of the user may affect users' sense of privacy in that people may feel that they are not alone (which can also be positive) or that they are being watched. If the user can control privacy levels, such problems can easily be overcome. SARs may also increase the level of privacy by side-stepping the need for human assistance for tasks which are potentially embarrassing or private (e.g. going to the toilet or getting washed). This may also serve to protect the user's dignity.

### **3.3.4 Autonomy and safety**

SARs could be used to carry out certain tasks on behalf of the user or to provide a sufficient level of support to enable the person to complete the task him/herself. This should promote the autonomy of the user. Cesta et al. (2007) divided the possible tasks of a domestic robot into two categories: on-demand interaction (in which the user takes the initiative and might ask the robot: have I taken my pills today, have I already had lunch or where are my keys?) or proactive interaction (in which the robot may detect certain programmed danger and warning scenarios such as the person lying on the kitchen floor, and take the appropriate action).

However, the degree of autonomy granted to the robot must be appropriate and carefully monitored, with the user retaining as much control as possible and if necessary, constant monitoring from carers or healthcare professionals (e.g. in the case of SARs dispensing medication) (Feil-Seifer et al., 2007). In the case of SARs designed to promote social interaction, a certain degree of autonomy of the robot is perhaps needed.

As people with dementia may at some point experience difficulties with mobility, vision and coordination, it is essential that SARs are stable and not likely to provoke accidents (e.g. through their colour, size, shape, movement or sound). In all cases, users need to feel safe using the robot and positive about it. People should avoid patronising those using various forms of assistive technology.

### **3.3.5 Dignity, truth-telling and confusion**

As people may feel more or less at ease interacting with SARs, the interaction promoted and required by the SAR may suit some people more than others. It could even be problematic if people realise that they are dependent on the SAR but feel ridiculous using it. It may remind them of the human contact that is not available to them. Some may be confused by the robot, not understanding how it works, what to do to make it work or what triggers its actions. As some people with dementia suffer from confusion and delusions, the use of SARs may lead to fears about intrusion in their home. It must be clear to them that they can get rid of the SAR if they don't like it and have access to alternative support for their needs.

Some of the ethical issues linked to doll therapy could be applicable to the use of companion robots. For example, it could be argued that the person with dementia who

comes to believe that the device is living is being deceived. A counter argument would be that not correcting the person with dementia concerning this belief provides them with the opportunity to participate in a rewarding and meaningful activity, and to adopt a nurturing role (Andrew, 2006). Such deception linked to good intentions is what Marzanski (2000) would call “justifiable benevolent deception”. Whether it is actually justifiable is a matter for debate. However, it must also be borne in mind that a person (adult or child) who acts as if an object is alive, does not necessarily believe that this is the case.

### **3.4 The use of AT to enhance safety and wellbeing in the home**

#### **3.4.1 Detectors and monitors fitted to everyday equipment and stand-alone devices**

Various devices and systems can be installed in people’s homes which result in a safer environment for people with dementia as well as peace of mind for them and their carers (provided that the devices and systems function properly and can be easily used). Such AT can therefore promote autonomy and safety. Blackman et al. (2003) suggest that despite attempts to create a safe environment where people have quality of life, there is a risk of the home starting to feel like a prison. They emphasise that supporting independence (e.g. through the use of AT) is no guarantee against exclusion and criticise disabling environments, adding that in some cases a person’s impairment may be removed by a suitable adaptation of the environment.

Buildings are now being constructed which incorporate as standard features various forms of AT such as cooker monitors (to detect gas, smoke and rings which have been left on), pictorial object locators, water level and temperature gauges, pressure sensors, automatically activated lighting and a range of other monitoring devices. Such buildings are sometimes called smart homes.

AT can be active (involving some purposive action on the part of the user) or passive (responding automatically to the behaviour of the user or to other conditions such as smoke, rising heat or water level). In the case of active AT, it is more likely that the person with dementia will be aware of it and have some degree of choice regarding its use once installed, whereas with passive AT, the user does not have the same degree of control, save uninstalling the equipment (not an easy task for many people) or getting rid of it. Different kinds of safety devices therefore have the potential to increase autonomy and safety but autonomy also involves the ability to choose and this may be affected by the type of AT used. When a person moves into residential care where such technology is used, it is possible that he/she will not be aware of the various devices used and will only find out later. In such cases, he/she would not have consented to its use as it was pre-existent and may be unhappy about its use.

There are also numerous stand-alone devices which may contribute towards self-esteem, autonomy, safety and wellbeing (as mentioned earlier depending on the devices, the

people involved and the situation) such as picture telephones, digital pens, calendar clocks and medicine dispensers. Some of these devices may enable people with dementia to maintain social contact with family, friends and the outside world thereby helping avoid social exclusion and helping ensure recognition of their personhood.

In the case of people who do not live alone, the extent to which certain devices are visible to others may affect their sense of pride and dignity. If too obvious, the people for whom they are intended may feel incompetent and embarrassed, especially if people visit and ask what they are for. If such devices were installed on a large scale as standard features, this would be less likely.

Some devices, such as movement sensor light switches, may be confusing if the person with dementia has forgotten either how they work or having consented to their installation. Whilst certain devices may be experienced as contributing towards autonomy and thus reassuring, for some people, they may serve as a reminder of their own loss of capacity, loss of personal control over their lives and disability (Gitlin et al., 1998).

In some cases, elderly people may rely heavily on the AT device or system to the extent that they trust it more than they trust their own judgement. If the device then malfunctions and gives out faulty information (e.g. regarding taking medication), they would be less likely to detect the error and this makes them vulnerable (Ho et al., 2005). Apart from the need to take this into account during the design of various forms of AT, regular review and maintenance of AT is needed. Providers of AT also have an obligation to ensure that it is safe and reliable, particularly when used by people who may not have the capacity to check this themselves.

As some devices for use in the home are fairly expensive, their use raises concerns about equity. Clearly, people with a higher income will have more opportunity to obtain them although some devices may be financed to some extent by the State. This will differ, however, from one country to the next and may be dependent on certain conditions such as whether one lives alone, the severity of one's condition and one's level of income.

Finally, service providers may be hostile towards the introduction of AT in the home as they may feel that it is a threat, seeing it as an alternative to the personal service they provide in the home (Magnusson and Hanson, 2003). There is possible agreement from carers and people with dementia that AT should not replace human contact but on the other hand, decisions about this are most probably influenced by economic concerns and as stated earlier, it is the quality of human contact that is important, not the quantity.

### **3.4.2 Monitors and alarms linked to the person and his/her activities**

#### **3.4.2.1 *Balancing discretion with transparency***

Enuresis monitors may be a source of shame, particularly if they are visible to others or known about. However, they may also promote dignity by preventing accidents from happening in the long run due to careful analysis of the times that accidents tend to

occur. Such monitoring may lead to the provision of timely support. Preventing enuresis may reduce embarrassment and the need to depend on others for hygiene needs and changing sheets, thereby also promoting autonomy.

As with most forms of AT, the visibility and invasiveness of the system may be disturbing to some people, especially those who do not need to use it. For example, it may be necessary to install a computer in the living room or monitors around the house or there may be visible wires and buttons. Certain equipment, such as hoisting devices, may be very obvious and cumbersome (check if this is the case). When obtaining consent for the installation of assistive technologies, cohabitants should therefore also be consulted as installation may represent an invasion of their privacy.

Finally, whilst it is important to make AT unobtrusive when fitted in people's homes, there is an argument in favour of making sure that it can be seen, especially in the case of equipment designed for monitoring purposes. Being able to see the equipment, to see when it is switched on and to control it (to the extent that the user has the necessary capacity) has implications for consent, autonomy and management of privacy issues.

#### **3.4.2.2 Privacy and autonomy**

AT for the monitoring of falls (or to signal distress) can be active or passive. Some systems require the person to press a button (e.g. on a pendant or phone), whereas others react to the detection of sudden impact or prolonged immobility. Those which do not require purposive action may involve some degree of invasion of privacy in that they may record and transmit information to other people about the user's activity. Some may even involve video monitoring. Systems which are more intrusive may nevertheless be most appropriate for certain individuals and permit greater autonomy.

Whilst various forms of AT may promote autonomy and provide safety, concerns are often expressed that AT should not be used to replace human contact. Indeed, one study found that the use of AT was in some cases dependent on a carer being present to remind the person to use it (Cahill et al., 2007). On the other hand, people with dementia have also expressed satisfaction about not having to rely on other people so in some cases, an advantage to AT could be that it enables people to express their independence. Talking about a night and day calendar, one person commented:

*"It's the best thing I've ever got, I don't have to ask Deirdre (caregiver) what day it is. It gives me a sense of... independence. I don't have to be running to Deirdre."* (quoted in Cahill et al., 2007, p.137)

### **3.5 The use of AT for memory and mobility**

#### **3.5.1 Autonomy and safety**

The use of televideo monitoring for the self-administration of medication by people in the early stages of dementia helps promote autonomy but also has implications for

safety. People using the technology may fail to respond to it or simply be out of the house when it is activated. This is not unusual as people in the mild stages of dementia, for whom the technology is mainly intended, may be leading fairly active lives and be less bound to the home than those in the later stages (Smith et al., 2007). They may also inadvertently switch off the monitor or camera. Such technology therefore has the advantage of promoting autonomy but may result in a false sense of security, which must be borne in mind when trying to balance the two principles. In a small-scale qualitative study in which 8 people using such a system were interviewed, it was found that some people appreciated the personal contact with the caller/operator which shows that technology can sometimes be combined with additional human contact rather than merely replacing it (Smith et al., 2007).

Determining who is granted access to the control of the AT is an important factor in the ethical use of AT. Provided that it would be safe to do so and that the person understands the consequences of doing so, the person using the AT should be able to switch it on and off, if and when required, as otherwise his/her continued consent to its use cannot be guaranteed.

AT can be used as a memory aid to enable people to carry out tasks which would otherwise be difficult or impossible to accomplish on their own due to difficulties remembering what to do, which items are needed for the task or which order to carry out each stage of the task. For example, a video prompt for every step needed to prepare a cup of tea or coffee can be used, based on a recording made in the person's own kitchen (Davies et al., 2010). This may enhance self-esteem and promote autonomy and well-being. However, the various capacities of people with dementia deteriorate over time. Consequently, there may come a time when the device no longer promotes autonomy but rather represents a risk for the person's safety (e.g. through scalding or electrocution).

Similarly, with a computer-based device which gives a reminder consisting of a symbol and text that a door has been left open (e.g. a door of the house or the fridge), it will only work if the person with dementia understands the symbol or text message and goes to close the door when the message is shown. If others with an interest in the safety of the person with dementia presume that the device is working, they may have a false sense of security and an alternative, perhaps more effective, approach would not be tried. Awareness of dementia and regular assessment of the person with dementia and the appropriateness of various AT solutions are therefore essential.

### **3.5.2 Proportionality, dependency and isolation**

It is important to respect the principle of proportionality which means that the level of intervention should be restricted to what is really needed for a particular person in a particular situation. Providing more assistance than is actually needed may result in the premature loss of remaining capacities which Kubitschke et al. (2009) argue may foster a new form of dependency (namely on AT rather than on other people) and that this may be experienced by some people as dehumanising and reducing dignity. Furthermore, if

the AT is introduced as a replacement for human assistance, the transferral of dependency may result in a loss of human contact, and hence in increased isolation.

### 3.6 The use of AT for surveillance, safety and monitoring

#### 3.6.1 Movement sensors/detectors

Sensors/detectors can be useful devices enabling carers to rest, sleep or attend to other matters in the safe knowledge that they will be alerted by a signal should the person with dementia get out of bed in the middle of the night or out of a chair perhaps during the day and possibly need assistance. In a residential care setting, such devices could make it easier to ensure the safety and the provision of assistance to a larger number of people at the precise moment that it is needed. A night-time monitoring was recently tested which allows zones of varying degrees of perceived danger to be identified and linked to varying tones of urgency (Spring et al., 2009). This device also permits the control box (where the signal is heard) to be placed in a different room to that where the person with dementia sleeps which was found to enhance privacy for both carers and people with dementia.

##### 3.6.1.1 *Safety and restriction of liberty of movement*

Although there is considerable evidence that restraint increases the likelihood of falling and also some evidence that it can lead to serious accidents and even death, people who have dementia or are confused are more likely to be restrained (Burton et al., 1992; Capezuti et al., 2002 and 2007; Gallinagh et al., 2001; Gastmans and Milisen, 2006; Sullivan-Marx et al., 1999). Kwok et al. (2005) investigated, by means of a randomized controlled trial, the use of pressure detectors to alert staff that elderly people in a convalescent hospital at risk of falling had moved from their bed or chair (i.e. so that they could be assisted by staff if necessary which would be preferable to using restraint). For one group of residents trunk restraint, bedrails and chair boards were used and for another group bed-chair pressure sensors were in addition made available to staff. No significant differences were detected in the number of falls, mobility, transferability or the amount of time that residents had to endure physical restraint. The researchers conclude that staff had only used the pressure sensors selectively as an additional means of safety. This suggests that AT may have the potential to serve as an alternative to the use of physical restraint (which can rarely if ever be justified on ethical or safety grounds) but that adequate training and explanation must be provided.

Movement sensors/detectors can also provide information at a distance that the person has not moved (i.e. that s/he has not remained immobile for a lengthy period of time) which could in some cases be an indication of a fall or problem. However, rather than providing a sense of security, such devices may in certain cases serve as a means of control or of imposing a daily rhythm on a person that is not his/her own. For example, a person may want to sleep or lie down for several hours during the day but fear triggering the alarm and so refrain from doing so.

### 3.6.1.2 Privacy

Movement sensors/detectors may be perceived as an invasion of a person's privacy. A senior citizen who had been trying out movement detector surveillance equipment complained about this and about the way she felt controlled:

*"I don't want people to know when I take a nap... when Toy [her dog] and I are lazy... that's only between him and I ... they know enough about me. I want to spare them my strange habits..."*

*"...at times when I can't sleep and get up in the middle of the night I sometimes think that this might be seen ... which makes me reluctant to do so!" (Essén, 2008, p.133)*

While (2006, p. 362) sums up the issue of privacy and control as follows:

*"Older people, like everyone else, are entitled to vary their daily routine without consultation and it should not result in the arrival of a rapid response care team to whom they have to justify their lie-in."*

Some devices can be used to monitor the behaviour of the user via their use of equipment (e.g. recording how many times he or she opens the fridge door or measuring the weight of the fridge), which might help determine eating habits and whether food is being eaten, hoarded or thrown away (Van Hoof and Kort, 2009). Whilst the person with dementia may be aware of the use of such devices and have agreed to their use, they may nevertheless feel embarrassed or humiliated if they perceive this as infantilisation or unwelcome surveillance. It is therefore necessary to ensure that these devices are as discreet as possible and that their use is kept confidential (particularly in nursing homes where people live in community with other people whom they do not necessarily know very well).

The intrusion of people's privacy can be limited by the type of equipment used. Movement detectors, such as the "just checking" devices described by Price (2007) can be used on a temporary basis in order to find out how a person behaves in his/her home in order to devise an appropriate care package. The devices are small, wireless and do not record any visual image. Access to the resulting chart can be controlled by a password protected website.

## 3.6.2 Electronic surveillance

### 3.6.2.1 Privacy, dignity and personhood

Electronic surveillance, which could include closed circuit television (CCTV) and video surveillance, takes monitoring a step further in that it adds the visual image of the person being monitored. CCTV is used extensively in the UK in the public domain but in some countries much less or hardly at all. In the private sphere of a person's home or living space, video surveillance could be considered an invasion of a person's privacy, involve a lack of respect, and constitute a threat to their dignity and personhood (in treating them like objects). There could also be a risk of voyeurism and using video recordings for criminal purposes. The Royal College of Nursing (2004) and the Mental Welfare Commission



for Scotland (2005) have suggested that electronic surveillance should be considered as a form of restraint. On the other hand, Essén (2008), who interviewed 17 seniors found that some perceived electronic surveillance as protecting their privacy as it enabled them to carry on living in their own homes instead of having to move into residential care. Säventedt et al. (2006) distinguish between the use of technology for plain surveillance or support, quoting one of their interviewees who stated:

*“It is very important that the person who controls the older person via the electronic device has some kind of connection with them and understands their problems. It cannot be just anybody because then it changes from support of older people to surveillance.” (p.20)*

It is therefore necessary to consider who should have access to video recordings, but also how and for how long recordings should be stored and the justification for using such devices. Should, for example, male carers have access to video recordings of female residents in nursing homes or residential care (or female carers of male residents)? This may be particularly relevant for people from certain cultural or religious backgrounds. In cases where special attire is required in public places (e.g. the burkha or the Sikh turban), the boundaries between the private and the public sphere may need to be clarified, especially in residential care settings (bearing in mind the way that each person interprets religious or cultural obligations). For some people with dementia, concerns over the use of surveillance equipment may be dependent to some extent on who is observing them (Robinson et al., 2007).

Also, there should be limits as to where electronic surveillance can be used (e.g. not in the WC or the bathroom). However, the use of AT must be considered on an individual basis as taking the example of the bathroom, the use of video surveillance might give the person more freedom, direct privacy and autonomy whilst they take a bath or shower than they would have if someone needed to be physically present. On the other hand, perhaps an alternative, less intrusive form of AT could be used which would provide a sufficient level of protection (e.g. from falls, scalding or overflows), enhance self-esteem and promote autonomy.

The home or a person's own room, in the case of communal living, is a very personal and private domain and people can usually decide whom they want to invite in. As with home care in general, but especially in the case of surveillance technology or tracking devices involving the intervention of other people, the same degree of privacy cannot be ensured. People may feel uneasy or even threatened by this invasion of their personal space and in the case of same-sex relationships, this may result in an undesired “outing”. Heterosexual couples might also prefer to keep their relationship private (e.g. due to ageist attitudes towards sexuality or tensions within the family).

### **3.6.2.2 Beneficence/maleficence and justification**

Surveillance equipment may be considered as contributing towards beneficence and maleficence. Electronic video equipment, for example, can be used by people with

dementia to identify visitors, protect against intruders and perhaps even reduce the likelihood of abuse or substandard care. Some relatives (or even people with dementia) arrange for video cameras (also known as “granny cams”) to be installed in the rooms of people with dementia living in residential care as a means to protect them against abuse (Bharucha et al., 2006). Provided that the person with dementia has consented to this and is currently aware of and in agreement with the use of the equipment, the resulting loss of privacy should not be problematic. However, it should be possible for the person to switch off the camera (or ask for it to be switched off if s/he cannot manage this alone) should s/he want a moment’s privacy (e.g. if s/he has an intimate relationship). The issue of privacy is also relevant to visitors who may feel uneasy about being observed. On the other hand, it has been suggested that the use of such equipment could make it even more difficult to attract and retain good staff due to the invasion of their privacy and fears about wrongful allegations (Bharucha et al., 2006).

Another argument is that constant monitoring might damage the personal bonds between people with dementia and professional carers (NewsMax.com, 2001). Nevertheless, with regard to the principle of justice, if some residents are able to have such surveillance and others not, and if such surveillance is effective, this could increase the likelihood of the abuse or inferior care of those residents who do not have it.

### **3.6.3 Tracking and tagging devices**

The main types of tracking and tagging devices are as follows:

- the direct tracking of a person by means of global positioning systems (known as GPS) which locates a person by satellite (due to an ankle or wrist device, a pendent or a mobile phone) and then transmits details of his/her location via a mobile phone network to a mobile phone, computer or call centre.
- tagging which involves the person with dementia wearing a special device (e.g. on the ankle or wrist) which emits a signal if the person leaves a designated area such as his/her home or garden. This can be combined with a numeric paging device which alerts the carer.
- access control systems (equipment which recognises a chip card and acts on the environment accordingly by locking or unlocking doors, blocking elevators and recording access to certain areas).
- the identification of a trail of locations which indicates where a person has been (known as breadcrumbing)
- the use of infrared technology to detect immobility within the home or that a person has not returned home by a certain time or has left the house at an unusual time such as in the middle of the night.

#### **3.6.3.1 Uses, benefits and practical problems**

Tracking and tagging devices may contribute towards privacy, freedom and autonomy as they may enable people to go somewhere on their own (e.g. for a walk, to the shops

or to visit someone) in the secure knowledge that if they get lost, it will be easier for others to find them. This also means that they are not dependent on someone else being available to accompany them and can choose when and where they would like to go. In some cases, a “geofence” may be erected (a virtual perimeter) which limits the freedom of people wearing a tag by emitting a signal if a person goes beyond a certain preset limit. However, this may still be a better alternative to a locked door policy (Bail, 2003).

Studies have shown that people with dementia who get lost are more likely to be permanently admitted to a care home than those who do not, so tracking devices may partly contribute towards the ability to lead an autonomous life (Balestreri et al., 2000; McShane and Skelt, 2009; Phillips and Diwan, 2003).

As the devices can also provide protection by ensuring that a person can be quickly found if they get lost, this can provide reassurance for carers (even if it is never actually necessary to track a particular person).

The above-mentioned benefits may be jeopardized by a number of factors. Such devices need batteries. Carers therefore need to remember to charge the batteries as if they run out, the person with dementia may be at greater risk. The devices should be fairly small and unobtrusive but this means that they can be easily misplaced. With regard to the actual technology used, there are sometimes problems with the accuracy of GPS readings as well as of those of the “geofence” (an additional function which sets a virtual perimeter). These problems can result in a false sense of security for both carers and people with dementia. In the context of residential care, this false sense of security may lead to reduced staffing levels (Welsh et al., 2003). Also, the setting of boundaries reflects the unequal power relationship between staff and residents and in the home setting may lead to a change in power relations between couples and between other members of the family and the person with dementia.

Finally, if tracking and tagging devices are used in settings where there is a shortage of staff or where available staff have a tendency to remain separated from residents and simply watch the recordings or wait for a signal that someone has crossed a barrier in order to react, the people with dementia using this type of AT may come to associate breaching the boundaries available to them with obtaining some kind of human contact (Mental Welfare Commission for Scotland, 2006). This would clearly be counter-productive as it could encourage “wandering” and create tension between residents and staff.

### **3.6.3.2 Conflict between autonomy and liberty, and safety/security**

As part of his theory of human motivation, Maslow (1943) formulated a hierarchy of needs in which each set of needs must be met before attending to the next set of needs. He claimed that people are preoccupied with ensuring that their basic physiological needs are met before turning their attention to their safety needs and only after that to higher order needs such as love and affection, and self-esteem. Under self-esteem,

Maslow included, amongst other things, the need for confidence in the face of the world, independence and freedom.

The use of tracking and tagging involves a conflict between safety/security and autonomy and liberty. Whilst most people are probably in favour of balancing respect for a person's rights with the perceived need to protect him/her, different groups of people (e.g. relatives and professional carers) may have different opinions on this issue. Opinions may also differ between people from different cultures (Landau et al., 2009).

In a few studies, carers have been reported to have a positive view of tracking and tagging devices but at the same time to be in favour of a greater degree of freedom and respect for the autonomy of the person with dementia (Melillo and Futrell, 1998; Nicolle, 1998; Robinson et al., 2007), although a French study found that 50% of carers were in favour of a substantial amount of surveillance of the person with dementia and 50% against (Rialle et al., 2008).

Health and social care professionals tend to be very much concerned about protecting all their patients and residents from harm and may be influenced by concerns about litigation (Robinson et al., 2007). These concerns may lead to dilemmas for nurses and day centre staff dealing with people with dementia whose freedom of movement cannot legally be restricted (i.e. they are voluntary patients or attend a day care centre on a voluntary basis).

A recent study comparing the attitudes of informal carers and professional carers towards the use of GPS and radio frequency identification (RFID) to track people with dementia highlighted the different attitudes of various groups of people (Landau et al., 2009). Through a statistical analysis procedure known as factor analysis, five factors reflecting types of attitude were identified, namely use for the sake of the patients' safety, use for caregivers' peace of mind, respect elders' autonomy, support restricted use and oppose use. The highest scores were obtained for the factor "use for the sake of the caregivers' peace of mind" and the lowest score for the factor reflecting objection to the use of the device. Respondents who were older had significantly higher scores for concerns about the caregivers' peace of mind and the patients' safety but lower scores for respect for the person's autonomy. No gender differences were found. When the scores of the two groups were compared it was found that informal carers of community dwelling people with dementia were significantly more in favour of the use of tracking for their own peace of mind and for the safety of the person. Professional carers obtained significantly higher scores for the restricted use of tracking (e.g. in severe cases when there was no suitable alternative) but informal carers were significantly more opposed to its use in general. This last finding contradicts the finding of some of the previously mentioned studies. Based on the scores of the informal carers, Landau et al. (2009) conclude that support for the use of tracking is mainly based on a desire for their own peace of mind (which is similar to the findings of Robinson et al., 2009 and Landau et al., 2010).

On the basis of a literature review, Robinson et al. (2007) concluded that it was not possible to draw conclusions about the perspectives of people with dementia on the use of AT to manage “wandering” as studies focused on carers’ views. In their qualitative study, carried out in 2006, which involved a focus group discussion with 6 people with dementia, the participants spoke about the benefits of walking and getting out which included getting some fresh air, independence, relieving tension, keeping fit and enjoyment. None of them described this as wandering.

### 3.6.3.3 *Managing risk*

Risk can be considered in relation to oneself, to another person or to a larger group of people. For example, if a person leaves a ring on the cooker switched on, he/she may later burn him/herself, someone else might burn themselves or if something inflammable is put on the ring, the whole kitchen might burn down, thereby endangering the lives of other people.

There may be differences in the perceptions of risk of people with dementia, carers and professionals, although most probably consider safety an important issue for people with dementia and some may believe in the necessity to aim for total safety. However, it could be argued that a total absence of risk is impossible and not even desirable. The Mental Welfare Commission for Scotland (2006) suggests that life is never risk-free and that some degree of risk taking is an essential part of good care. People may be more protective of others, than they would be of themselves (Nuffield Council on Bioethics, 2009), particularly in cases where the person being “protected” is considered in some way vulnerable.

Historically, risk was considered as something that could be either good or bad, resulting in loss or gain, but Lupton (1999) claims that it has been transformed into something that is entirely negative. Kemshall (2000) claims that in the context of social and healthcare, which is guided by a managerial discourse, risk is viewed as something that is objective and measurable, and hence can be acted upon although frontline staff might sometimes find the official policy of an organization inappropriate or unhelpful for specific cases. Others argue that it is socially constructed and value-laden (Lupton, 2005). It must be borne in mind that everyone is different and that people have different perceptions of danger and different assessments of the level of risk they are willing to take. An example of this, not linked to dementia, is smoking which has been proven to be damaging to health but many people with full mental capacity consciously continue smoking and believe it is their right to do so. Imposing one’s perception of risk onto someone else deprives them of their autonomy and freedom, and in some cases may affect their well-being.

A person’s position regarding the relative importance of safety and autonomy may depend on whether they are personally responsible for the safety and wellbeing of the person with dementia (Landau et al., 2010):

*“When the patients are in the community and the family caregivers feel they have the ultimate responsibility for the patients’ well-being, the family caregivers favor the need for safety more than the right to autonomy and privacy. In the study by Robinson et al. (2007), family caregivers claimed that dementia patients in nursing homes were overprotected. Thus, professionals prefer autonomy more than safety when patients are in the community, but safety more than autonomy when under their care in nursing homes.” (Landau et al., 2010, p.415)*

However, Landau et al. (2007) also point out that many people with dementia in nursing homes are there because their relatives feel that they are no longer able to assure their safety within the community so the characteristics of the two groups may in some cases be different.

It is also important to consider the definition of “lost”. What constitutes lost might not be the same thing for the person with dementia and his/her carer and this may lead to conflict or to a breach of the person with dementia’s privacy and right to freedom (Hughes, 2008). However, there is a risk of erring on the side of safety and of the automatic presumption that the carer knows best which in some cases would be paternalistic and based on stereotypes of people with dementia lacking capacity and awareness. According to Martin et al. (2010), paternalism aims to protect people from themselves and involves an assumption that their safety is more important than their liberty.

Any potential dangers linked to the use of the device itself must also be considered and communicated to the person or people responsible for consenting to its use. Undesired reactions to the use of implanted RFID tags in animals have been reported such as adverse tissue reaction, migration of the device, electromagnetic interference and even tumours, and as Foster and Jaeger (2008) point out, few humans have been implanted with such devices so data on possible risks are not yet available.

#### **3.6.3.4 Allocation of responsibilities**

Systems designed to monitor or track people and their movements generally involve more than just technological devices as their use is dependent on people who are responsible for the information they provide and aware of the necessity to respect confidentiality. This raises various questions such as who is and should be responsible, how should their behaviour be monitored and controlled and what is the hierarchy of responsibilities? This is not usually inherent in the design as it could be organised in a number of different ways. It also raises the issue of justice mentioned earlier in that it may be presumed that some members of society, such as women, are more available than others. Moreover, informal carers are not always able or willing to take on the responsibility of looking for the person if and when s/he gets lost (McShane et al., 1998). Their consent to becoming involved in the functioning of the system cannot be presumed.

### 3.6.3.5 *Painful memories*

An interesting argument reported by Heeg et al. (2005) against informing people with dementia that a tagging device had been implanted in their shoes was to avoid triggering memories of psychiatry in the third Reich<sup>6</sup>. In the reported case, carers were informed and their consent obtained. This raises the issue of the use of devices which might be perceived as restricting liberty of movement with people with prior experience of deprivation of liberty, humiliation and stigmatization (e.g. through war, incarceration, serious bullying or membership of certain groups). There may also be a perceived injustice of being deprived of liberty as expressed by an elderly veteran (in connection with physical restraint) who stated, "I have done nothing to deserve this. To think you fought a war – now I am a POW<sup>7</sup>" (Sullivan-Marx, 1995, reproduced in Dawkins, 1998, p. 25). These examples also emphasize the importance of bearing in mind the personal history and cultural issues associated with each person.

### 3.6.3.6 *Privacy*

Concern has been expressed about tagging and tracking devices failing to respect a person's privacy (Dawkins, 1998; Department of Health, 2001). Two aspects of privacy have been identified: 1. the freedom to escape being observed or accessed when desired, 2. the freedom to escape observing and reacting to others (Essén, 2008; Sidenvall, Fjellstrom and Ek, 1994). This could include avoiding the undesired access by other people to one's own personal space (Rössler, 2005).

Clearly, tracking devices may prevent people from getting away from others and from having a moment's privacy, but at the same time may prevent others from encroaching on one's personal space.

However, in communal living situations, this possible advantage would only occur if there were some prior agreement as to what constitutes one's personal space and would have to be balanced against other people's right to freedom of movement.

### 3.6.3.7 *Dignity and personhood*

The use of tagging has been likened to assault, an attack on civil liberties and a form of restraint (Cassidy, 1994; Hughes and Campbell, 2003), particularly when used on a person who is incapable of consent, but some argue that it is nevertheless preferable to physical or chemical restraint which is dehumanising and risky (Bail, 2003; Wrigglesworth, 1996). However, as physical or chemical restraint is rarely justifiable, this is not a convincing argument to override ethical concerns about the use of tagging. Moreover, as pointed out by Hughes (2003), straitjackets were initially considered more humane than shackles but this doesn't make either acceptable. Even when walking about is considered by others as problematic, there are perhaps other solutions such as modifying the environment or looking for reasons why the person is walking about (Stokes, 2002). Arguing against the use of restraint for people with mental illness, Dawkins states his opinion that "people have unconditional worth and dignity that supports a strong argument for the maintenance of autonomy, even in the event of possible harm from an

6 The German State from 1933 to 1945

7 Prisoner of war

injury” (Dawkins, 1998, p.26). Such an argument could be applied to the use of AT which may involve a restriction of liberty (in order to protect) or alternatively increased liberty and autonomy (perhaps also involving a slight risk), but each situation could be seen from different perspectives depending on the actors involved.

According to Cahill (2003), tagging should have no place in dementia care as it removes personhood. O’Neill (2003) states, “tagging should be reserved for babies, convicted criminals and animals.” Others would argue that tagging and tracking technology is suitable for use in dementia care provided that it is applied in a way that respects personhood and maintains functional capacity (College of Occupational Therapists, 2005 – in Plastow, 2006; McShane et al., 1994). However, people with dementia may still feel that the use of such devices implies that they are irresponsible and in need of constant surveillance (Landau et al., 2009).

In an earlier study which involved a survey of family and professional carers, only 18% reported concern that the use of tracking or tagging devices would result in a loss of dignity (Nicolle, 1998 in Robinson et al. 2007). However, this is a fairly old study and perceptions may have changed [also need to obtain details of the study to see how representative it was]. According to interpersonal theories of personhood, personhood is maintained through genuine contact, and lack of human contact may lead to social withdrawal, the objectification of the person with dementia and non-respect of the person’s dignity. Consequently, if AT devices led to reductions in staff or reduced levels of interaction with residents in nursing homes, this could adversely affect dignity and personhood (although clearly it is the quality of the contact rather than its quantity that is important).

#### **3.6.3.8 Stigmatization**

People who acquire disabilities later life may find the use of AT shameful and stigmatizing (Bjørneby et al., 1999; Brickfield, 1984; Häggblom Kronlöf and Sonn, 1999; Luborsky, 1993 and Zimmer and Chappell, 1999). Particular concerns have been expressed about the possible stigmatizing impact of tagging on people with dementia. Dementia, like a number of other health conditions, is already unfortunately considered a stigma by many people and experienced as such. The use of AT may, in some cases, draw attention to the fact that a person has dementia. In the context of health-related conditions, stigma has been described as follows:

*“Stigma is typically a social process, experienced or anticipated, characterized by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group. The judgment is based on an enduring feature of identity conferred by a health problem or health-related condition, and the judgment is in some essential way medically unwarranted. In addition to its application to the persons or group, the discriminatory social judgment may also be applied to the disease or designated health problem itself with repercussions in social and health policy. Other forms of stigma which results from adverse social judgments about enduring features of identity apart from*



*health-related conditions (e.g. race, ethnicity, sexual preferences) may also affect health; these are also matters of interest that concern questions of health-related stigma.” (Weiss and Ramakrishna, 2004, p. 13)*

However, the term stigma does not only refer to the complex social phenomenon described above but also to specific attributes which, due to the meanings attached to them, are considered discrediting and lead to stigmatization (Goffman, 1963; Jones et al., 1984). The attribute (an enduring feature of identity; sometimes but not necessarily a physical or visible mark) serves to identify those people who belong to the out-group (i.e. “them” not “us”). In the case of electronic tagging or even tracking, having the electronic device on one’s person can serve as a stigma. Tagging has been used for newborn infants, criminals, failed asylum seekers and animals (O’Neill, 2003; Carvel, 2005; Corsi, 2008), as well as to prevent the theft of clothes in stores (Counsel and Care, 1993). Marr (1989) and Welsh et al. (2003) suggest that the same stigma linked to the tagging of people within the penal system could be extended to people with dementia.

An additional link to criminality can be found in the origins of the term “stigma” which date back to ancient Greece where people were physically marked by burning or cutting as a visible sign to others that there was something bad or unusual about their moral status (Goffman, 1963). It was a sign of disgrace and/or a signal to other members of society that the bearer was in some way flawed or deviant, a kind of lesser person. In most cases, this kind of treatment was reserved for slaves, criminals or traitors. The marking of human beings in this way involves an element of dehumanisation and objectification.

Consequently, the electronic tagging of people with dementia can be stigmatizing as the devices serve as a sign to other people of a potentially discrediting difference and also due to the association with criminality. If the device is obtrusive, the person wearing or carrying it may feel infantilised or incompetent, or it may draw attention to their medical condition. Even if the tagging device cannot be seen, the consequences of wearing it may become apparent if ever the alarm is activated as a result of crossing a virtual geographical barrier. This is similar to the use of chair and sensor pads in communal settings where the signal may result in a person being regarded with shock or disapproval and being labelled as “the one making all the noise” (Morgan, 2003).

The issue of visibility/concealability fits in with Goffman’s distinction between being discredited on the basis of a stigma and being discreditable. The former describes the situation whereby the stigma is known about (e.g. everyone can see the device and knows what it is) whereas with the latter, the stigma is not immediately apparent (or at least the person does not think that it is) but risks becoming apparent (e.g. by crossing a boundary and hearing an alarm or being brought back). According to Corsi (2008), an implantable chip is marketed in the United States for use with people with chronic diseases including Alzheimer’s disease. Niemeijer and Hertogh (2008) suggest that the use of implantable radio frequency identification technology (RFID) may actually be less stigmatizing to the wearer than a bracelet as it is not visible. However, the person with the implanted chip is

likely to eventually forget that he/she has it and from that point on would not be aware that he/she was being tracked. In Germany, 23% of about 1000 respondents taking part in a survey organised by a lobby group BIKOM stated that they would be willing to have a chip inserted under their skin “for certain benefits” but 72% were completely opposed to having any electronics in their body (The Local, 2010).

However, the actual stigma (in the sense of the identifying mark) is rarely the real root of the problem as it depends on the meanings attributed to it. Not everyone interprets tagging and tracking in the same way and some people may be in favour of using such devices for themselves for various reasons and even express this in advance directives. Moreover, meanings are culturally constructed and can therefore change.

The meanings that people attribute to electronic tagging have not been systematically evaluated but there have been a couple of small-scale qualitative studies which involved asking people about their perceptions of tagging. In a small-scale telephone survey of carers and a feasibility study involving 24 people with dementia, when asked what tagging reminded them of, several said the tagging of criminals (Hughes and Campbell, 2003). A couple of other people made references to being on a lead and wearing a cow-bell. Further information is needed to determine how people with dementia feel about electronic surveillance, tracking and tagging, and also to see how this relates to the views of carers and healthcare professionals.

If electronic tagging becomes more common for different groups of people (e.g. people with dementia and infants), if its use and design is discussed with all actors concerned and if it is presented in a positive light by the media, negative associations with criminality might gradually be reduced. “Universal design” (Mace, 1985), sometimes referred to as “inclusive design”, involves trying to design products and environments which can be used by “all people, to the greatest extent possible, without the need for adaptation or specialised design” (Connell et al., 1997). Perry, Beyer and Holm (2009) suggest that designing AT according to the principle of universal design and paying attention to the way things look will reduce the likelihood of the item or system being stigmatizing. This might be possible in some cases but it may prove difficult to design certain devices which could be used by older users whilst remaining attractive to younger or more experienced users (Hawthorn, 2003). Wallace et al. (2010) question whether universal design is always appropriate and even desirable.

Mace (1998) criticised the lack of attention paid to aesthetics in the design of AT but this is perhaps gradually changing. With regard to disability, this might include ramp access to buildings (not as an alternative but as the only access) or large, easy to grip utensils with attractive handles which could be mass produced and not marketed as utensils for disabled people. The choice of AT could still be tailored to the individual needs of anyone using them.


### 3.6.3.9 *Access control systems and breadcrumbing*

With access control systems, access to designated areas is controlled automatically. If a person has a chip card which grants access to a particular area, it will be detected and the door unlocked or the lift activated. The equipment can also be used to record the access of each person carrying the chip card. Margo-Cattin and Nygård (2006) suggest that such technology promotes privacy, protection of property and a sense of security in that residents realize that access to their private living space is strictly controlled. They also point out that the automatic locking and unlocking mechanisms of doors may help individual residents find their way to their own rooms by limiting the number of wrong options, thereby promoting autonomy and leading to a sense of accomplishment.

One possible drawback to the access control systems is that it would become clear that different residents had different levels of access to specific areas other than their living space, such as balconies, gardens and kitchens. This could be used as a form of social control or punishment. Even if used fairly and with respect, some residents could feel awkward about being publicly denied access to certain areas, especially if they do not understand the reasons for the restriction, and this would not promote their wellbeing. This requires sensitive management of this type of AT so as to minimize the possibility of upsetting residents and maximise potential benefits to residents of such technology linked to freedom of movement, autonomy and wellbeing.

Finally, “breadcrumbing” and the use of infrared technology could be interpreted as an invasion of personal privacy if the person is not aware of its use. Non-authorized use of such equipment would amount to spying on someone. Care must also be taken to ensure that the person fully understands what they are agreeing to. The devices should be explained in terms that are easy to understand bearing in mind that potential users might not have a particularly good understanding of technical matters but not over-simplified so as to hide the full extent of the possible functions and the implications of using the device. Also, it should be possible for the person with dementia to know in advance whom to ask for the device to be removed and how much this would cost.

- **In Chapter 3 we have examined the ethical issues linked to the use of assistive technology for and by people with dementia. We have drawn attention to the positive impact that AT can have on people’s lives as well as some potential dangers or drawbacks which can hopefully be avoided or minimised through increased awareness and communication as well as through careful planning and monitoring. In the next section, we will provide practical guidelines on the ethical use of AT by and for people with dementia.**



*Alzheimer Europe's  
guidelines and position on  
the ethical use of AT for/by  
people with dementia*

## **4 *Alzheimer Europe's guidelines and position on the ethical use of AT for/by people with dementia***

This section contains guidelines for ethical decision making (i.e. suggestions of things to bear in mind when trying to come to a particular decision). It is impractical and perhaps even undesirable to try to make absolute recommendations based on the application of particular ethical principles. Ethical decision making is a complex task, situations are rarely in effect identical and even those which seem to be so, involve different people who may have different perspectives and have different culturally-determined assumptions. It is nevertheless possible to provide some general guidelines and to share our position on certain issues.

When writing this document and drafting these guidelines, we were targeting a very wide audience consisting of informal and professional carers, policy makers, service providers, voluntary workers, emergency and security forces (such as members of the police force and fire brigade), researchers, AT designers and last but not least, people with dementia for whose benefit AT is intended and who should be kept involved in decisions relating to its use.

### **4.1 Contemplating the use of AT**

- 4.1.1 Dementia should be recognised as a disability. Consequently, the entitlement of people with dementia to AT should be recognised.
- 4.1.2 The possible use of AT should be carefully assessed within the context of an overall care plan for a particular person, in a particular situation with specific needs, capacities and wishes. It should not be simply as a decision about whether to use a certain device or system or to use a device because it is available). The aim should not be to find a single, ready-made solution that can be applied to everyone or in all situations.
- 4.1.3 The main decisive factors should be that the AT, if used, is for the benefit of the person with dementia. An assessment of needs, risks, benefits and functional capacity should therefore be performed prior to implementing AT.
- 4.1.4 When considering what might be beneficial for the person with dementia and promote or maintain his/her functional capacity, his/her known or presumed, past and current interests, values, opinions, preferences and life history should be borne in mind but should not determine the response.
- 4.1.5 Other people with an interest in the issue should also be consulted (such as relatives, carers, legal representatives/guardians and professional carers).

Perceived benefits and drawbacks for all concerned should be openly discussed.

- 4.1.6** Whilst AT should not be used solely to reduce staff costs, the real situation must nevertheless be borne in mind (i.e. is it likely in a particular situation that additional funds will ever be made available to take on additional staff to provide the necessary assistance that AT could provide).
- 4.1.7** When considering the use of AT, the following factors should be considered:
  - 4.1.7.1** whether the specific form of AT is proportionate to the need and justifiable and whether there are possible alternatives such as human assistance, other types of equipment or altering the environment or procedures;
  - 4.1.7.2** possible reasons for the behaviour or ways of addressing the situation which has led to the possible necessity to use AT;
  - 4.1.7.3** the likely consequences of using AT, or on the contrary of not using it, as well as possible alternatives. This should include a consideration of possible losses (e.g. of human interaction or contact) linked to its use;
  - 4.1.7.4** legislation, guidelines, codes of deontology, safety regulations and the possible wider implications for the person with dementia of using AT;
  - 4.1.7.5** the hopes and expectations of the person with dementia linked to the use of AT (e.g. whether they are realistic or likely to lead to disappointment);
  - 4.1.7.6** the interaction between the person, his/her capacity, the environment and the task or purpose for which AT could be used;
  - 4.1.7.7** the reactions of significant others and implications for them linked to the use of AT or of having systems installed in their home;
  - 4.1.7.8** the possibility that a particular form of AT might actually be a covert or overt means of restraint.

#### *Managing risk*

- 4.1.8** When faced with decisions about the use of AT which necessitate balancing the management of risk with the promotion of the person's autonomy, the following should be considered:
  - 4.1.8.1** the real rather than hypothetical risks involved;

- 4.1.8.2 the necessity to focus on risks to the individual and not primarily on risks to the establishment (care home or hospital);
- 4.1.8.3 considering potential benefits at the same time as potential risks;
- 4.1.8.4 people have different perceptions of risk and of what level of risk is acceptable to them;
- 4.1.8.5 it is unrealistic and even undesirable to try to eliminate every possible risk in the life of the person with dementia. Moreover, this would be likely to have a negative impact on their quality of life;
- 4.1.8.6 in residential settings, people are not cared for in isolation. Decisions taken for one person (e.g. linked to safety or promoting autonomy and wellbeing) may have an impact on other residents. Consequently, care staff may need support in managing competing interests in order to find the best solution for all concerned;
- 4.1.8.7 the need to develop a structure with clear guidelines within which to make decisions about safety in which the risk of litigation and respective responsibilities in such cases are clear;
- 4.1.8.8 staff should have an opportunity to discuss safety issues/risk management with all concerned and to make a record of the conclusions;
- 4.1.8.9 blanket restrictions linked to the use (or non use) of AT should be kept to the minimum and regularly reviewed.
- 4.1.9 The use of assistive technology for the purpose of restraint (rather than to promote autonomy):
  - 4.1.9.1 has been linked to accidents and even death. Consequently, the use of restraint (which may sometimes be combined with AT) for alleged safety purposes should be carefully assessed and only used with extreme caution;
  - 4.1.9.2 should be the last resort and its necessity and possible alternatives regularly reviewed.

*Doing what is best/most beneficial for the person with dementia*

- 4.1.10 It should be considered whether and if so how the use of AT:
  - 4.1.10.1 would promote autonomy (e.g. enable the person with dementia to make decisions, foster remaining skills, help develop/acquire new skills, live as independently as possible and desired etc.);

- 4.1.10.2 would be beneficial to the person with dementia;
- 4.1.10.3 would respond to the needs and wishes of the person with dementia, and where appropriate, his/her carers;
- 4.1.10.4 respects or corresponds with the cultural traditions of the person with dementia;
- 4.1.10.5 would respect or endanger his/her dignity;
- 4.1.10.6 might be harmful to the person with dementia (e.g. physically, psychologically, emotionally, with regard to his/her relationships with other people);
- 4.1.10.7 might contribute towards the stigmatization of the person with dementia (e.g. negative labelling and stereotyping, considering them as part of out-group, devaluation and discrimination);
- 4.1.10.8 the extent to which the person with dementia has to adapt to the AT or vice versa.
- 4.1.11 When trying to determine what is best for a person who does not have the capacity to decide him/herself or to communicate his/her wishes, it may be necessary to try to find the right balance between what is in his/her best interests (which is not necessarily what s/he would prefer) and what s/he would probably really want, based on his/her past, known, recorded and presumed wishes and indications of his/her wishes based on his/her currently observed behaviour and reactions.
- 4.1.12 When considering whether a particular form of AT threatens the dignity of the user, an attempt should be made to look beyond one's own values and consider the life history of the person with dementia as well as his/her currently expressed needs, wishes and feelings.

*Eligibility and access to AT*

- 4.1.13 When determining eligibility criteria:
  - 4.1.13.1 people with dementia should have access to AT when it would be most suitable and beneficial to them, not solely on the basis of severity of their condition or their financial situation;
  - 4.1.13.2 although people who are living on their own may have a greater need for certain forms of AT to enable them to carry on living in their own homes, the availability of informal carers, for those who do not live alone, should not in



itself result in access to AT being denied (as this would involve an assumption that they would provide the care);

- 4.1.13.3 attempts should be made to ensure that people on a low income have equal access to AT;
- 4.1.13.4 a system of renting out AT should be envisaged for people who cannot afford the more expensive items of AT and who are not eligible for financial assistance;
- 4.1.13.5 care should be taken to ensure that people with dementia have equal access to AT compared to other potential user groups (such as people with physical impairments or learning disabilities) and that they are not discriminated against on the basis of age, mental health status, age or any other criterion.
- 4.1.14 Access to AT should be rapid and flexible so as to provide a timely response to current needs. It should be possible to return without difficulty or financial penalties any devices or systems that are no longer needed or appropriate (e.g. in cases where AT is rented out or provided by the State or charitable associations rather than purchased privately).

*Specifically linked to tracking and surveillance technology*

- 4.1.15 Tracking, surveillance and monitoring technology can be used to enhance or restrict freedom, promote or override autonomy and respect or disregard people's desire for privacy. Different people may have different objectives and perceptions linked to the use of this kind of AT which may affect how they feel about using it, enhance their quality of life and promote their well-being or alternatively, lead, for example, to unhappiness, frustration, distress and low self-esteem. In order to increase the likelihood of a positive experience using this kind of AT, the following points should be considered:
  - 4.1.15.1 This form of AT should not be used indiscriminately as people have very different needs;
  - 4.1.15.2 In residential care, careful planning is needed to ensure that only the people who need this kind of AT use it;
  - 4.1.15.3 Devices and systems should be switched off and only switched on if and when required;
  - 4.1.15.4 People with dementia should not be tricked into using tracking or monitoring devices;

- 4.1.15.5** The use of AT for surveillance or monitoring should not replace human contact or serve merely to reduce the number of staff needed to take care of people;
- 4.1.15.6** Breaching a barrier should not automatically result in the person with dementia being returned to his/her place or room as the appropriate response may sometimes be to engage with the person or accompany him/her beyond the barrier;
- 4.1.15.7** When considering the use of a video monitoring device within the home or within a residential care setting, the religious customs and convictions of individuals should be respected (e.g. women who wear a burkha, or Sikh men who wear a turban should not be filmed without their consent when not wearing it);
- 4.1.15.8** Monitoring of movement or video surveillance linked to an alarm system should be sufficiently flexible to give a person some leeway in the organisation of his/her daily routine or to signal temporary changes so as not to feel controlled by the system itself (e.g. not permitting oneself to have a lie-in for fear of setting off the alarm);
- 4.1.15.9** The criteria for the stimuli necessary to set off the alarm should be discussed with the person with dementia (if possible) and with other members of the household in order to ensure that it fits in with their way of life and daily routines and that those of outsiders are not imposed on them (e.g. not daring to have a lie-in lest the alarm for immobility goes off);
- 4.1.15.10** In addition to live monitoring of people using surveillance, tagging and tracking devices, note should be taken of common patterns of behaviour which might permit a more tailored care plan (e.g. including activities or social contact at certain times of the day);
- 4.1.15.11** Devices should be discreet so as to avoid stigmatization and users experiencing shame and low self-esteem. Such discretion should include not only the visual aspect of the devices but also the volume and visual aspect of the alert signals to carers and staff (which can be seen or heard by other people);
- 4.1.15.12** Audio recording (i.e. of what people say) is unlikely to be justifiable in most situations. However, in some situations, it might be more suitable than video monitoring, especially if the device can be adjusted to prevent details of conversations being audible;
- 4.1.15.13** Video recording should not be permitted in rooms with toilet facilities and seldom in bathroom areas as this could be construed as an invasion of pri-

vacy and lack of respect for a person's dignity. Also, it could lead to people avoiding these rooms and feeling stressed or humiliated. Alternative solutions to ensure a person's safety and provide any necessary assistance should be found;

- 4.1.15.14 The use of video surveillance in sleeping areas should also be avoided unless strictly necessary;
- 4.1.15.15 In cases where video surveillance is used in a person's sleeping area, it should be possible to switch off the recorder in order to have some privacy when required;
- 4.1.15.16 If the person is not capable of switching off the machine him/herself, it should be possible to make a simple verbal request without there being any need to provide justification or unreasonable advanced notification.

## 4.2 Organisation and implementation

### *Consent*

- 4.2.1 As a general guideline, the issue of consent should be approached from the perspective of shared decision making, involving people with dementia, carers and health and social care/service providers, in a collaborative effort to define mutually acceptable goals of care or support.
- 4.2.2 The consent of the person with dementia by/for whom the AT will be used should be sought irrespective of the complexity of the technology or stage of the disease.
- 4.2.3 If s/he lacks the capacity to give informed consent, the consent of his/her carer or legal representative should be sought. The person with dementia may have sufficient capacity to state which carer or carers s/he would like to be consulted.
- 4.2.4 Many people with dementia live alone and therefore do not have a carer. Some might not have a legal representative either. In such cases, consent to AT would have to be granted in accordance with the rules and regulations of each country concerning contractual capacity, the cost of the equipment and the probable impact on the potential user.
- 4.2.5 People providing proxy consent should bear in mind the past and current, resumed or known wishes and preferences of the person with dementia. Past wishes may be important but the possibility to have different current wishes should be accepted.

- 4.2.6** If the person with dementia lacks the capacity to give informed consent, s/he should be consulted, his/her assent should be sought and s/he should be kept informed of any further decisions linked to the use of AT.
- 4.2.7** The capacity to consent should be considered as being separate from other forms of consent (e.g. a person may lack the capacity to make a will or drive a car but still be able to consent to the use of a home alarm system or a flood detector).
- 4.2.8** Before consent or assent is given, those concerned must have been fully informed about the AT (e.g. how it works, its purpose, possible implications of using or not using it, possible disadvantages, costs involved and likely response when used etc.).
- 4.2.9** In some cases, consent to various aspects of a device or system should be sought separately (e.g. consent to live video monitoring and consent to video recordings being stored).
- 4.2.10** Whenever possible, an alternative to the system or device should be proposed so as to avoid there being any form of covert coercion (e.g. if you do not accept this system, you will have to go into residential care).
- 4.2.11** As some forms of AT may be fairly complex and as people with dementia are likely to have difficulties with language, comprehension and memory, a real effort to enable the person with dementia to understand the relevant issues linked to the decision should be made (e.g. including the use of diagrams, straightforward text and practical demonstrations).
- 4.2.12** Service providers should consider ways to allow people with dementia to test the AT before making a final decision. This could involve a trial phase of several weeks after which they could return the equipment without any penalty/additional charge.
- 4.2.13** Even if the person with dementia has the capacity to consent, the support of his/her carers should ideally be sought, particularly for forms of AT which require their intervention or which may affect their privacy.
- 4.2.14** It should not be presumed that informal carers or relatives will contribute towards the effective functioning of an AT system (e.g. being the contact person for tracking systems or home alarms, operating computerised systems or reminding the person to use the AT).
- 4.2.15** In the context of professional care, people who are directly and personally affected by the use of AT (e.g. it involves them being filmed, recorded or their

whereabouts monitored) should, at the very least, be informed of the use and implications of AT for them so that they can decide whether or not they wish to continue working under such conditions.

- 4.2.16 Organisations and service providers should develop an ethics protocol linked to the use of AT in residential care and within the community. This should be signed by those taking responsibility for the use of the device or system.
- 4.2.17 As people with dementia are likely to forget that they have consented or that a certain device is being used, confirmation of their consent (or assent) should be sought from time to time. This is particularly important in the case of monitoring or tracking devices which may be increasingly used as the person's condition deteriorates, resulting in a greater invasion of their privacy than they originally agreed to. Written information could serve as a useful reminder.
- 4.2.18 When choosing a residential or semi-residential care establishment or day care centre, people with dementia and any others involved in making this choice should be informed of the use of any AT in the establishment or centre which could be construed as limiting personal freedom.

#### *Training and guidance*

- 4.2.19 Professional carers and service providers should be trained in how to communicate with people with dementia so as to increase the likelihood of them being able to obtain informed consent. They should also be trained in ethically thinking.
- 4.2.20 When AT is installed or provided, training should be given to everyone involved on how to use it.
- 4.2.21 Care should be taken to ensure that the person with dementia has understood and is confident about how to use the device or system.
- 4.2.22 Training should be accompanied by advice on the appropriate choice and use of AT, covering its benefits, disadvantages, possible risks and implications for users, as well as regular updates on what is new in the field.
- 4.2.23 The extent to which the person with dementia can manage the control of the AT should be ascertained.
- 4.2.24 During training, the right level of control should be given to the person with dementia so that s/he can feel in control of the system or device and not feel stressed or threatened by it.

- 4.2.25 The person with dementia and his/her carer or legal guardian should be informed what to do in case of problems with the AT and whom to contact.
- 4.2.26 Plans (or protocols for professional carers) should be prepared which can be used when things go wrong (e.g. in case of power cuts, loss of devices or the person responsible for computerised devices being absent).
- 4.2.27 Plans (or protocols for professional carers) should be in place regarding the maintenance and periodic adjustment of AT devices and systems.
- 4.2.28 A climate of trust and a positive approach to problem solving should be fostered so that the person with dementia or his/her carer or legal representative are not made to feel incompetent if they encounter problems using the AT and hence reluctant to report difficulties.
- 4.2.29 It should be made clear how to dispose of the AT when it is no longer needed or required.
- 4.2.30 Any costs linked to the removal of the system should be clarified and the name and contact details of the person dealing with this communicated before installation takes place.

*Involvement of professional carers (for residential and home-based care)*

- 4.2.31 In the case of tracking, tagging, surveillance and monitoring devices and systems, procedures and responsibilities of professional carers should be made clear and recorded in the individual care plans of people with dementia.
- 4.2.32 Details of anyone allowed to view recordings of video surveillance should be disclosed, if requested, to those using the devices and/or their carers or legal guardians.
- 4.2.33 A record should be kept of any other person accessing video recordings or watching live recordings of a person with dementia, professional or informal carers, or visitors.
- 4.2.34 The right to privacy of professional carers (for whom the video surveillance is not personally intended) should be considered and, if necessary, they should be provided with a private unmonitored rest area.
- 4.2.35 Service users or their carers or legal representatives should have access to the names and job titles of the people authorised to access video recordings of the person with dementia.

### **4.3 How AT is used and its ongoing use**

**4.3.1** Measures should be taken to ensure that:

**4.3.1.1** AT is not being used in a way that infringes on a person's civil liberties, as a form of coercion, in an abusive manner or as a means of social control;

**4.3.1.2** confirmation that the person with dementia still agrees to the use of AT is sought at regular intervals;

**4.3.1.3** changes in the way that AT is perceived over time as well as changes in the capacities of the person with dementia are taken into consideration;

**4.3.1.4** the use of AT is not perceived, especially in residential care settings, as granting privileges to some people and not to others or as a form of punishment (even if this is clearly not the intention of those in charge of its use);

**4.3.1.5** AT is used discreetly so as to avoid inadvertently "labelling" the person using it as this may contribute towards stigmatization or lead to self-stigmatization including feelings of shame, humiliation, social withdrawal and low self-esteem;

**4.3.1.6** the device or use of a system is not perceived by the user or others as ridiculising, infantilising or undignified;

**4.3.1.7** the device or system does not draw unnecessary attention to a problem that is embarrassing to the user or threatens his/her dignity (as perceived by the user or other people);

**4.3.1.8** AT does not provide a greater degree of assistance than that which is actually needed (perhaps due to a lack of time or assistance to enable the person to accomplish the task alone), thereby leading to a premature deterioration of the person's remaining capacity;

**4.3.1.9** the use of AT is not stressful and does lead to, or increase, confusion;

**4.3.1.10** AT used for leisure or recreational purposes appeals to the current wishes and interests of the person with dementia;

**4.3.1.11** AT for leisure or recreational purposes is not imposed on people (e.g. in order to occupy a large number of people with a limited number of staff or because it reflects the values or philosophy of life of those organising such activities);

- 4.3.1.12 conflict over perceived ownership as well as attachment issues linked to the use of socially assistive devices/robots are effectively addressed and if possible avoided;
- 4.3.1.13 people with dementia feel in control of the AT they are using, especially in the case of socially assistive devices/robots;
- 4.3.1.14 any negative experience with AT is investigated and a personalised solution sought because the same device or system can be used and perceived in different ways by different people;
- 4.3.1.15 concerns are taken seriously, however strange or illogical they may seem (in some cases, they may be based on a lack of information or a distorted perception of reality due to the consequences of dementia but nevertheless real concerns to the person with dementia).
- 4.3.2 A certain degree of visibility of the device may be unavoidable or necessary but care can be taken not to draw unnecessary attention to it. This may require special effort in residential care settings or wherever people live together (not only regarding the physical visibility of the device or its use but also in the way that professional carers or relatives talk about it in public).

## **4.4 Constant assessment**

- 4.4.1 Once operational, a system should be established to review the use of AT, provided that the person is in agreement. This should cover needs, benefits, risks and functional capacity and such assessment should be constant as a person's condition and situation may change rapidly.
- 4.4.2 Possible reasons for decreased interest in a particular device or system, difficulties using it, failure to see the benefits of it or simply forgetting to use it should be explored. People should not feel under pressure to use AT or be penalized for not using it. Instead, service providers should seek to understand the problem and then attempt to provide an appropriate response.
- 4.4.3 Reviews should involve the views of the person with dementia, carers and professionals. As with consent, every reasonable attempt should be made to enable people with dementia to communicate their views.
- 4.4.4 Attention should be paid to possible ways in which the use of AT has an impact on existing relationships and power relations. Should this occur, measures should be taken to help people deal with these issues.



- 4.4.5 The review process should be carried out in a constructive way with every attempt made to avoid making people with dementia and carers feel that they are being tested or judged.
- 4.4.6 As the use of AT should be part of an overall care plan, a review of its use should reflect this too.
- 4.4.7 The review should assess whether specific forms of AT are still appropriate for the person with dementia in view of his/her changing needs, capacities and living situation.
- 4.4.8 The information obtained from such reviews should be used to assess the appropriateness and desirability of its continued use.
- 4.4.9 Provided that consent has been obtained from users, anonymised data from such reviews should be made available to interested parties (e.g. AT manufacturers and researchers) to enable them to improve the design and use of AT for people with dementia.
- 4.4.10 Care should be taken to ensure that people are not left without assistance if AT is eventually withdrawn or proves to be ineffective.

## **4.5 The ongoing development of AT and its commercial distribution**

- 4.5.1 Research and development into AT should be user-driven. Researchers and AT developers should actively involve people with dementia and informal and professional carers in developing, testing the effectiveness and assessing the usefulness of various devices and systems.
- 4.5.2 People with dementia and informal and professional carers should be encouraged to share their ideas and discuss their problems with researchers and AT developers so as to stimulate the development of new forms of AT and ensure that devices and systems correspond to the needs and wishes of potential users.
- 4.5.3 Researchers and AT developers should take into consideration not only information about difficulties linked to various impairments but also of the needs and wishes of potential users (e.g. linked to feelings of independence, control, aesthetics and ease of use).
- 4.5.4 Information materials, produced with the assistance of people with dementia, as well as courses or workshops should be made available to AT designers

to enable them to familiarise themselves with dementia and to develop AT which corresponds to their needs and wishes.

- 4.5.5** As a high percentage of people with dementia are elderly, the design of AT for their benefit or use should incorporate features to facilitate their use of the device or system (e.g. taking into account possible difficulties with sight, hearing, mobility and dexterity).
- 4.5.6** Researchers and AT developers should obtain the necessary ethical approval for all studies and consultations involving people with dementia, carers and professional carers. If the study does not qualify for assessment by a recognised ethics committee, advice should be sought from an Alzheimer association.
- 4.5.7** In countries or situations where research into the development and assessment of assistive technology is either not regulated by ethics committees or not considered as research, guidelines and codes of conduct should be established, especially when people with dementia are involved.
- 4.5.8** A protocol for the management of personal data should be established. Only personal data that is necessary for the study or product development should be obtained, it should be rendered anonymous if possible, it should not be used for any other purpose than that for which it was obtained without the person's permission and it should be destroyed at the end of the study or within a reasonable period of time thereafter. All other provisions of data protection laws should be respected.
- 4.5.9** Commercial providers also have an ethical responsibility towards potential users of AT in the context of dementia. They should provide information to potential users about the possible implications of the use of various devices including possible drawbacks, risks and alternatives. The information about products should be easy to understand and not make any exaggerated or unfounded claims.
- 4.5.10** Commercial providers who deal directly with potential users of AT devices or systems should encourage potential users to discuss with the relevant organisations how to incorporate their product into the care plan of the person with dementia. In the case of AT for leisure purposes, advice could be provided on how the device might also be used to enhance social interaction and wellbeing.





*An ethical framework  
for making decisions  
linked to the use of AT*

## 5 *An ethical framework for making decisions linked to the use of AT*

In Chapter 2, we examined some of the main ethical principles and in Chapter 3, we explored the possible ethical implications of using various types of AT. As time goes by, these implications are likely to change as people change and are influenced by the values and practices within society at any given moment in time (e.g. by education, politics, religion, the economy and culture). In this Chapter, we propose a framework for decision making. A few techniques to help clarify ideas as well as a flowchart of the ethical decision-making process can be found in Annex 2.

### 5.1 An ethical framework for decision making

Whilst philosophers have provided in-depth analyses of the ethical principles underlying various moral and ethical issues, when it comes to making decisions in concrete situations, which are sometimes messy, confusing and involving competing principles, it is clear that trying to balance these principles is not an easy task and can lead to ethical dilemmas. Having provided concrete guidelines and recommendations aimed at highlighting some of the key issues linked to making ethical decisions about the use of AT, we would like to propose an ethical framework to guide such reflection and concrete decision making.

**When trying to make ethical decisions in the context of the use of AT for or by people with dementia, it is important:**

- To understand dementia as a disability
- Not to lose sight of the person
- To be aware of ethical issues and dilemmas
- To consider the interests and wellbeing of the person with dementia
- To consider principles, perspectives and paradigms

#### **Understanding dementia as a disability**

In Chapter 1, we looked at different ways of understanding dementia. We emphasised that it is not just about plaques and tangles in the brain but that factors such as personal history, coping skills, relationships with other people and one's own personality are equally important. An important part of this holistic perception of dementia is recognising that people with dementia have impairments and that these impairments often result in disability. Disability is not limited to people with physical impairments.

Recognition of dementia as a disability (or potential disability) is essential and the first step towards ensuring the appropriate design of AT to be used by or for people with dementia, but also towards ensuring that people with dementia have access to it when it

would be of most benefit to them. For some people, recognising dementia as a disability may involve changing their perception of dementia or of disability.

### **Not losing sight of the person**

People with dementia are our relatives, friends, neighbours and in some cases even work colleagues. They are also citizens, who will have contributed towards society in different ways for many years and may still be able to do so.

As the disease progresses, people with dementia may find it increasingly difficult to communicate their thoughts, feelings, ideas and emotions but they still have them. In such cases, the responsibility for initiating and maintaining contact may have to gradually shift to other people. This may involve adapting the way one communicates and being more attentive to non-verbal communication. At times, people may feel that they can no longer get through to the person with dementia (especially in the case of more advanced dementia) but the person is still there, still a valuable human being and perhaps, more than ever, still in need of human contact. It is essential to recognise the person with dementia as a person irrespective of the stage of the disease.

Difficulties communicating, time constraints, stereotypes and lack of knowledge about dementia may lead to the exclusion of people with dementia in discussions about the use of AT. If one overlooks or fails to recognise the uniqueness of each person, there is a risk that they will come to be considered as an object, a kind of generalised person with dementia. There is no single solution for everyone with dementia as their individual situation, personality, environment and condition are different. The same AT device or system may be enabling, useful, useless or irritating depending on the person using it or for whom it is used. It is therefore important to recognise the uniqueness of each person with dementia.

### **Being aware of ethical issues and dilemmas**

Whilst it would perhaps be incorrect to say that there is never a right or wrong answer to ethical dilemmas, many people would agree that finding the best ethical solution to a problem is by no means a simple matter. It may be necessary to find the right balance between competing principles and between possible benefits and disadvantages for different people depending on the situation and who is involved. But above all, it may be difficult to recognise what the key issues are or even whether there are any ethical issues involved. For this reason, it is important to make a conscious effort to consider what the ethical issues in a given situation might be and to consider the implications of different possible outcomes.

### **Considering the interests and wellbeing of the person with dementia**

The interests and wellbeing of the person with dementia must always come first in decisions relating to the use of AT for or by people with dementia. Every attempt must be made to communicate with the person with dementia in order to find out what he/she

wants and how he/she would feel about various options. When communicating with someone with dementia, some of the following techniques may help:

- maintaining eye contact
- frequently using the person's name
- placing oneself at the same height and talking face to face
- speaking slowly and clearly but not exaggeratedly so
- only asking one thing at a time
- using affirmative sentences
- paying attention to body language
- using gestures and touch (unless it is clear that the person does not appreciate being touched)
- giving the person plenty of time to think and respond
- going over what has been said at various points during the conversation
- providing visual support (e.g. jotting down pointers as to what has been said, using photos, sketches and diagrams, providing a summary and giving the person time to read through it before deciding)
- using one's imagination and creativity to look beyond the words to the message that the person is trying to convey
- keeping discussions short
- being attentive to whether the person might be tired, confused or lacking concentration

In addition, people can try to put themselves into the shoes of the person with dementia and also think how they would like to be treated if ever they were in a similar situation. Activities such as reminiscence work, scrap books or diaries may be useful ways of getting to know the person.

If the person with dementia is living in the community amongst relatives and friends, it may be easier to find out what his/her interests are. However, it must be borne in mind that people's interests may change over time, with or without dementia, and that the interests of the person with dementia may be in conflict with those of his/her carer. Some forms of AT may be beneficial to informal or professional carers but the main aim of AT is to assist the person with dementia and consequently, his/her interests and wellbeing must take precedence. Moreover, it should be borne in mind that some people have dysfunctional relationships in which they do not have each other's best interests at heart.

## Considering the three Ps

### *Principles*

In Chapter 2, we briefly examined various ethical theories and principles. The relevance of these principles will vary according to the specific characteristics of the problem and the situation, including the people involved. As technologies develop and new products become available, different ethical dilemmas may arise and other or additional principles may become important. Part of ethical decision making involves identifying and examining the ethical principles that are most relevant to the issue.

### *Perspectives*

In every situation, there will be different people trying to make sense of the situation, understand what is needed and determine the best solution. Each person will be approaching the dilemma from a different angle (based on his/her knowledge, situation, relationship to others concerned, personality and own experience of life) and will therefore have a different perspective to that of the others. Although the main benefit of the device or system should be for the person with dementia, understanding the perspectives of all concerned is vitally important as the person with dementia is not an isolated unit but rather part of a complex system. Some of the other members of that system may be important for the good functioning of the chosen device or system and the continued wellbeing of the person with dementia. They have their own rights and the ethical issues related to a particular solution may affect them too.

### *Paradigms*

Drawing on the later work of Hope and Oppenheimer (1997), members of the ENABLE<sup>8</sup> team (Marshall et al., 2000) emphasized the importance of paradigms when faced with the necessity to make decisions with ethical implications. The term paradigm has been used in a number of ways but the online encyclopaedia, Wikipedia (2010), provides a useful analogy, describing it as

*“a habit of reasoning, or “the box” in the commonly used phrase “thinking outside the box”.*

Marshall et al. (2000) used the term in connection with a reference situation (a vignette) which has some similarity to the current situation but for which the ethical issues are somewhat clearer and consequently, possible solutions to the current problematic situation can be evaluated against this comparable situation. For example, one could step outside the box and ask oneself whether a particular solution would be considered acceptable and fair in the case of a person with a learning disability, a younger person or a person of the opposite sex. In this way, a consideration of paradigms can have a double function of helping decide on the best solution and helping avoid various forms of discrimination (e.g. based on age, mental capacity, gender etc.).

<sup>8</sup> A project involving five countries aimed at facilitating independent living of people with early dementia and promoting their wellbeing through access to enabling systems and products.



## Annex 1 – Examples of ethical principles in legal documents and various conventions

### National Constitutions

The principles of dignity and privacy can be found in the constitutions of several countries, examples of which include:

Belgium	<p>Article 22 [Privacy]</p> <p>(1) Everyone has the right to the respect of his private and family life, except in the cases and conditions determined by law.</p> <p>Article 23 [Dignity]</p> <p>(1) Everyone has the right to lead a life in conformity with human dignity.</p>
Spain	<p>Article 10 [Human Dignity, Human Rights]</p> <p>(1) The dignity of the person, the inviolable rights which are inherent, the free development of the personality, respect for the law and the rights of others, are the foundation of political order and social peace. (.../...)</p> <p>Article 18 [Honour, Privacy, Home, Secrecy of Communication]</p> <p>(1) The right of honour, personal, and family privacy and identity is guaranteed.</p>
Latvia	<p>95. The state protects the honour and dignity of persons. Such behaviour against a person as torture, other cruelty or abasement of dignity is prohibited. No one may be subjected to a punishment which is merciless or debasing to the dignity of a person.</p> <p>96. Everyone has the right to the inviolability of a private life, place of residence and correspondence.</p>
Czech Republic	<p>Preamble</p> <p>We, the citizens of the Czech Republic in Bohemia, Moravia and Silesia, at this time of the reconstitution of an independent Czech State, (.../...), resolved to build, protect and advance the Czech Republic in the spirit of the inalienable values of human dignity and freedom as the home of equal and free citizens who are aware of their obligations towards others and of their responsibility to the community, ...</p>

Hungary	<p>Article 54</p> <p>(1) In the Republic of Hungary everyone has the inherent right to life and to human dignity. No one shall be arbitrarily denied of these rights.</p> <p>(2) No one shall be subject to torture or to cruel, inhuman or humiliating treatment or punishment. Under no circumstances shall anyone be subjected to medical or scientific experiments without his prior consent.</p> <p>Article 59</p> <p>(1) In the Republic of Hungary everyone has the right to the good standing of his reputation, the privacy of his home and the protection of secrecy in private affairs and personal data.</p>
Slovakia	<p>Article 16</p> <p>(1) The right of every individual to integrity and privacy shall be guaranteed.</p> <p>This right may be restricted only in cases specifically provided by a law.</p> <p>(2) No one shall be subjected to torture or cruel, inhuman or degrading treatment or punishment.</p> <p>Article 19</p> <p>(1) Everyone shall have the right to maintain and protect his or her dignity, honour, reputation and good name.</p> <p>(2) Everyone shall have the right to be free from unjustified interference in his or her private and family life.</p> <p>(3) Everyone shall have the right to be protected against unjustified collection, disclosure and other misuse of his or her personal data.</p>

**European and International Conventions and Declarations**

References to ethical principles can also be found in the United National Universal Declaration of Human Rights, the European Convention on Human Rights and the European Convention on Human Rights and Biomedicine.

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

***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; (.../...)

Resolving to take such measures as are necessary to safeguard human dignity and the fundamental rights and freedoms of the individual with regard to the application of biology and medicine,

***Article 1 – Purpose and object***

Parties to this Convention shall protect the dignity and identity of all human beings and guarantee everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine.

***Article 10 – Private life and right to information***

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

***Article 11 – Non-discrimination***

Any form of discrimination against a person on grounds of his or her genetic heritage is prohibited.

**Universal Declaration of Human Rights**

**(adopted by the United Nations General Assembly on 10 December 1948)**

***Preamble***

Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world.

***Article 1***

All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.

**Article 3**

Everyone has the right to life, liberty and security of person.

**Article 5**

No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment.

**Article 7**

All are equal before the law and are entitled without any discrimination to equal protection of the law. All are entitled to equal protection against any discrimination in violation of this Declaration and against any incitement to such discrimination.

**Convention for the Protection of Human Rights and Fundamental Freedoms (Council of Europe, 1950, came into force in 1953)****Article 3. Prohibition of torture**

No one shall be subjected to torture or to inhuman or degrading treatment or punishment.

**Article 5. Right to liberty and security**

1. Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law.

**Article 8. Right to respect for private and family life**

1. Everyone has the right to respect for his private and family life, his home and his correspondence.

**Article 14.**

The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.

**The European Social Charter (revised) (Council of Europe, 1996)****Article 15**

Disabled persons have the right to independence, social integration and participation in the life of the community.

**Article 23 – The right of elderly persons to social protection**

- to enable elderly persons to choose their life-style freely and to lead independent lives in their familiar surroundings for as long as they wish and are able, by means of:
  - a) provision of housing suited to their needs and their state of health or of adequate support for adapting their housing;

- b) the health care and the services necessitated by their state;
- to guarantee elderly persons living in institutions appropriate support, while respecting their privacy, and participation in decisions concerning living conditions in the institution.

***Part V, Article E, Non-discrimination***

The enjoyment of the rights set forth in this Charter shall be secured without discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national extraction or social origin, health, association with a national minority, birth or other status.

**International Covenant on Economic, Social and Cultural Rights (United Nations, 1966, entered into force in 1976)**

***Preamble***

Considering that, in accordance with the principles proclaimed in the Charter of the United Nations, recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world,

Recognizing that these rights derive from the inherent dignity of the human person,

***Article 1***

1. All peoples have the right of self-determination. By virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development.

***PART II***

***Article 2***

2. The States Parties to the present Covenant undertake to guarantee that the rights enunciated in the present Covenant will be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

## Annex 2 – Techniques to help come to a decision

### Imagining

Oppenheimer (1991) suggests that by following a line of reasoning through to its logical extremes and analysing the problem in different ways (including considering it from different perspectives), it is possible to see whether possible conclusions are “in accord with moral intuition”. Before doing this, other non-ethical issues linked to the situation need to be identified and acknowledged.

Whilst it is not advisable to just go along with your gut feeling, a nagging feeling that something simply isn’t right should indicate the need for further reflection.

It may help to think of a role model (e.g. a former teacher, your mother or a more public figure) and then imagine what they would think about your proposed decision.

Alternatively, you could imagine how you would feel about your reasoning and decision being made public (e.g. through a newspaper article or your friends and neighbours discussing it) (HENT, 2002). This doesn’t mean that you should be influenced in your decision by what others might think but that you should hopefully feel comfortable with the reasoning behind your decision.

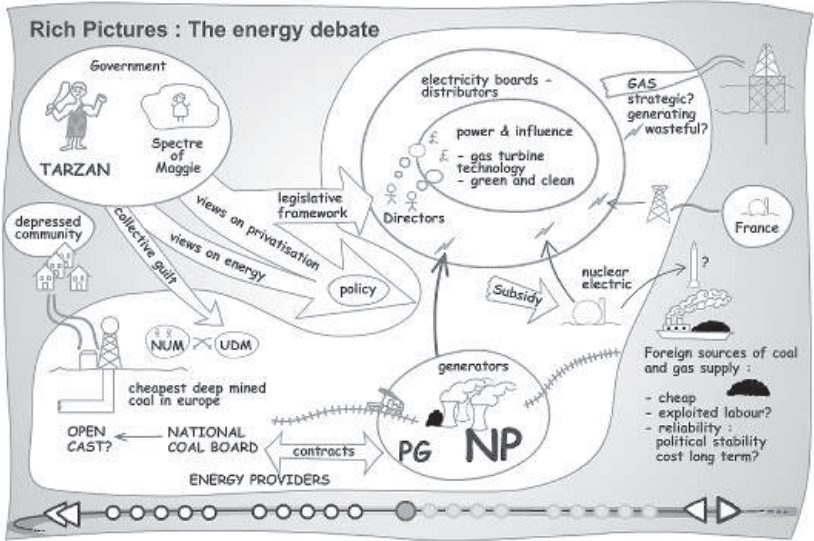
### Visualising the problem

It may help to put your thoughts down on paper. This allows you to think about the issue, leave it for a while and then come back to it and consider it anew. It also helps make sure that you haven’t overlooked something. Some people make sense of things better in visual form. A few points jotted down or sketched may also serve as useful memory aids when discussing issues with people with dementia, and can be a good way to get people talking about the issue. Here are a few examples:

### *Drawing a rich picture*

A rich picture is a diagram containing words, images, cartoons and symbols, linked to the main theme which is usually placed in the middle. Although they originated in the context of managerial decision making as a starting point for understanding human activity systems (Checkland, 1981, Checkland and Scholes, 1990), rich pictures can be drawn to describe processes, events, concepts and problematic situations, such as making an ethical decision. The important issues can be highlighted and links between the various issues can be shown. Making a rich picture is an iterative process which involves trying to understand a situation and refining that understanding. The picture may highlight contradictions, different perspectives and missing information (Monk and Howard, 1998). The following is an example of a rich picture about energy usage.

Figure 1: Example of a rich picture

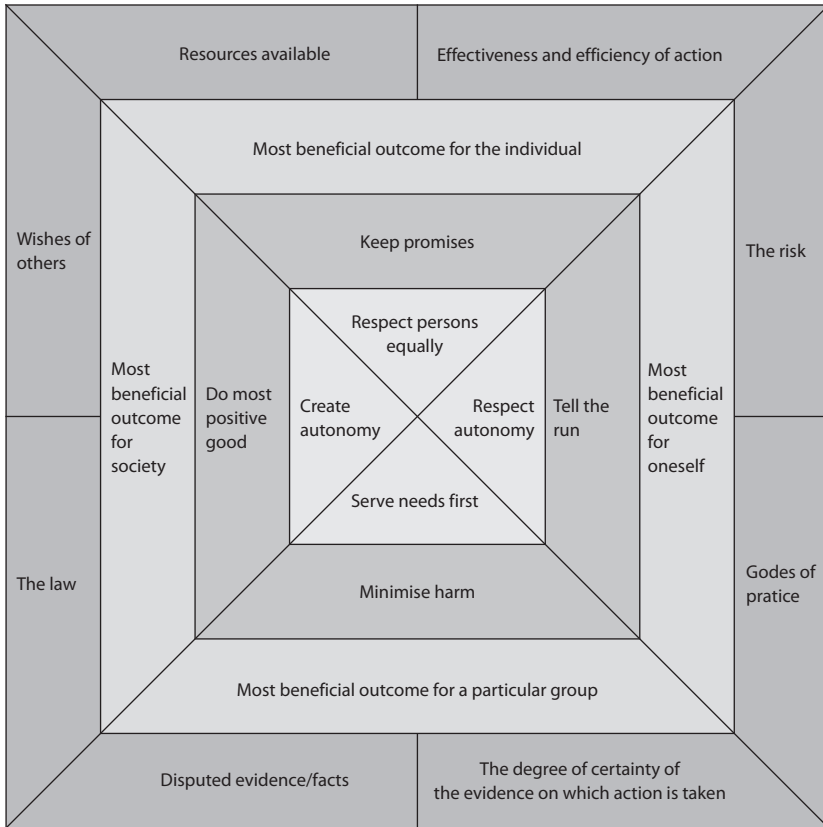


(Source: Open University)

### ***The ethical grid***

Another approach is to look at ethical dilemmas as if they were part of a spider's web, with each idea being linked to the others by a series of routes. Seedhouse (1998) displayed this graphically as a grid with four concentric layers (which could also be considered as looking down on a pyramid). The outer (bottom) layer represents organisational issues, the next outcomes for different people involved, the one above that, general principles and finally at the top, factors closely linked to the individual.

Figure 2: Seedhouse's ethical grid (in Stutchbury and Fox, 2009)



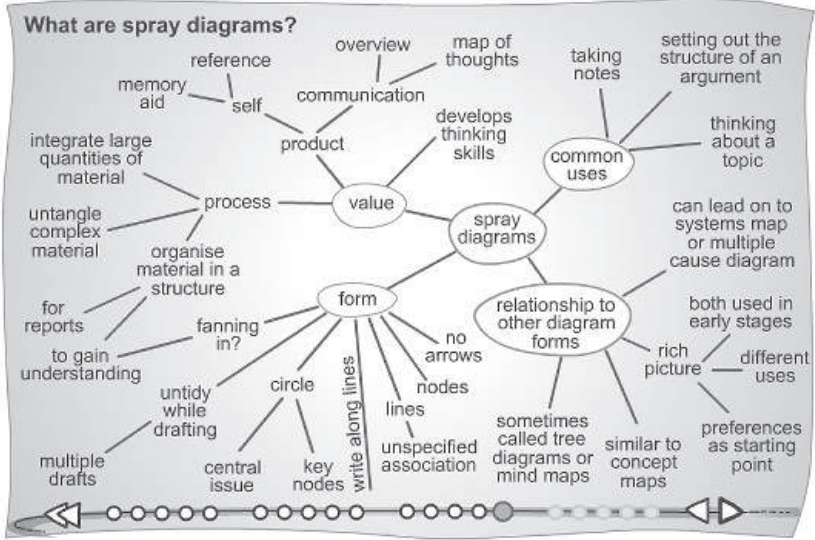
*Spray diagrams and mind maps*

Rich pictures and the ethical grid might be particularly useful tools for starting a group discussion and getting input and different perspectives from others (e.g. in family meetings or staff meetings). If you just want to jot down your own ideas, there are a few simple possibilities.

Spray diagrams are simple ways of presenting different arguments, looking at the relationships between ideas, whereas mind maps, which are quite similar, are more about brainstorming on your own and just getting your ideas down on paper, even in a relatively unstructured way. The following diagram and the rich picture above were provided by the Open University and guidelines for constructing such a diagram can be found at: <http://systems.open.ac.uk/materials/T552/>



Figure 3: An example and explanation of a spray diagram



(Source: Open University)

### Decision-making flowcharts

The techniques described above are useful tools which can be used in the context of the whole decision-making process. On the next two pages, you will find flowcharts which provide an overview of the decision-making process. These are just two perspectives on how to approach ethical decision making but they may be of some help in organising your ideas and planning your course of action.

The first flowchart was developed in the context of the Technology, Ethics and Dementia (TED) project (Bjørneby, Topo and Holthe, 1999). It is specifically aimed at ethical decision making in the context of dementia and technology and is based on the experience of the partners in the TED project. The flowchart provides concrete steps on how to decide on the appropriate and ethical use of AT starting with the initial assessment of the living situation of the person with dementia continuing right up to the point of the assessment of the final solution once implemented. As such, it is less about ethical dilemmas and more about how to avoid them.

The second flowchart is an amended version of one developed by the American Speech-Language-Hearing Association (2010). It represents a more general approach to ethical decision making and handling ethical dilemmas.

In both cases, at every step of the way, the opinions of the person with dementia should be respected.

Figure 4: Steps in the decision process (Bjørneby, Topo and Holthe, 1999)

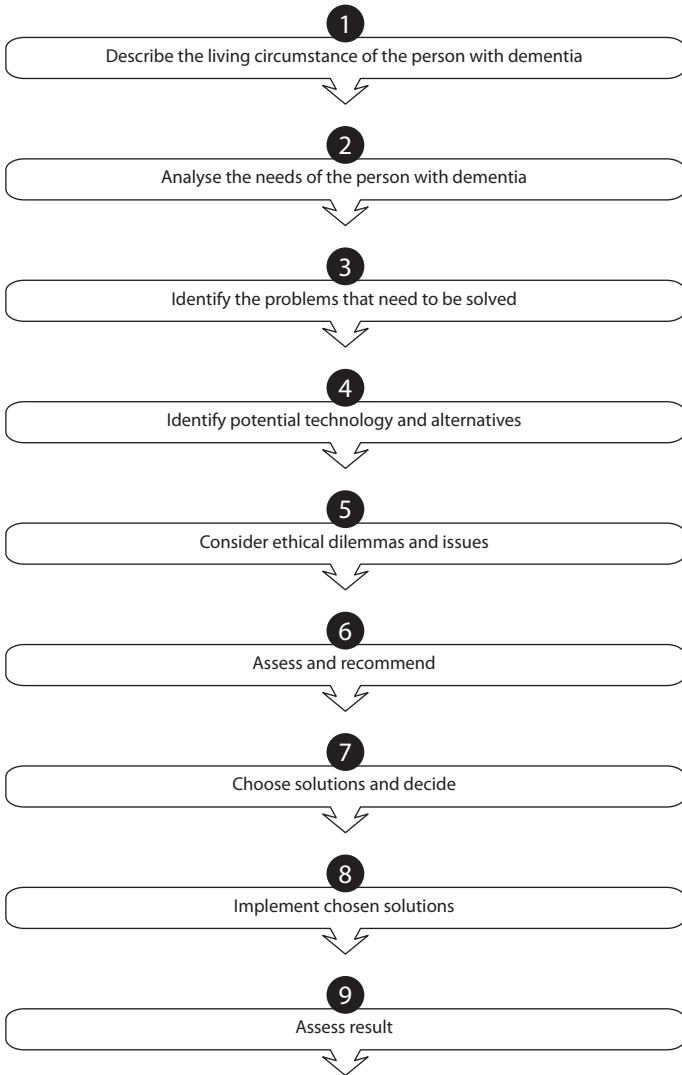
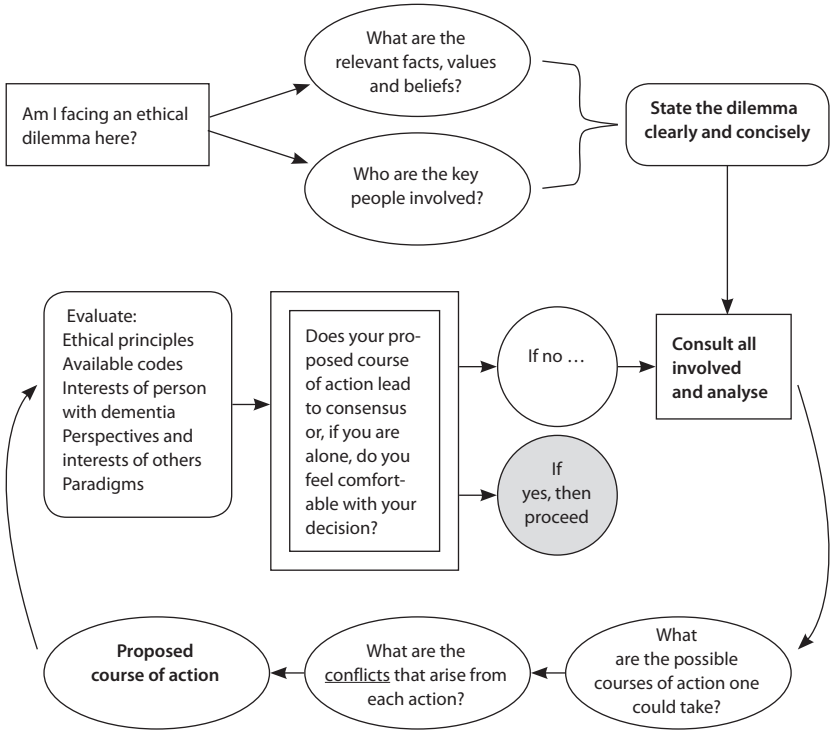


Figure 5: Flowchart of the ethical decision-making process (adapted from the American Speech-Language-Hearing Association flowchart, 2010)



## Glossary

Aetiologically heterogeneous	The causes of the disease and mode of operation are varied.
Aphasia	Difficulty understanding the speech of others and/or expressing oneself verbally.
Apraxia	Inability to properly use a known object
Agnosia	Lack of sensory-perceptual ability to recognise impressions from one or more of the senses.
Carer	In this text, the term carer is used to refer to a person who takes care of someone with dementia on an informal basis (i.e. it is not part of their paid employment even if in some countries some carers receive a small payment from the government in recognition of their valuable work). Often carers are relatives but this is not always the case which is why we do not use the term "family carer". In most cases, they did not choose to become a carer but circumstances of life resulted in them becoming one.
CCTV	This is the abbreviation for closed-circuit television systems which usually consists of a television camera, a video monitor and a transmission medium (e.g. a cable, fibre or wireless). Such systems are often used to monitor public spaces or premises.
Cross sectional survey	A survey which is carried out on a group of people at a specific moment in time (e.g. rather than every 5 or 10 years)
Enuresis	Urinary incontinence
Executive functioning	The ability to plan actions and change plans when adaptation is necessary
Impairment	Weakening, damage or deterioration (e.g. as a result of injury or disease).
Neuropathology	Pathology of the nervous system
Pathological	Resulting from the disease

Professional carer	People who care for people with dementia in the context of paid employment are referred to in this text as professional carers. Sometimes, to clearly differentiate between the two types of carers we use the terms “informal carer” and “professional carer”. This distinction does not imply any difference in the quality of care provided by either.
Randomisation	A method to ensure that the participants in a study were chosen randomly (so as to avoid involving people who all have something in common as this might contribute towards misleading results).
Video recording	We are using “video recording” as a general term to cover any type of recording of a person’s image regardless of whether the recorded image is stored, live, digital, on a film reel, with or without sound etc.

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