

Alzheimer Europe Report



Ethical issues linked to restrictions of freedom of people with dementia

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Preface

Preface

This report entitled “Ethical issues linked to restrictions of freedom of people with dementia” addresses the ethical issues surrounding the loss of freedom which many people experience as a result of having dementia. Such restrictions include those relating to residence or place of stay (i.e. involuntary detention or attendance in nursing homes, hospitals and day care centres), to the use of various forms of restraint (i.e. physical, chemical, psychological and environmental), to the right to live one’s life according to one’s values, preferences and wishes and finally, to the right to play an active role in society (e.g. marrying, voting, making a will and driving).

Most of these issues have already been explored by Alzheimer Europe insofar as they relate to legislation and clearly the right to live a life that is free from unjust, inappropriate or unnecessary restrictions is often both a legal and ethical issue. However, in this report, we focus on the ethical implications of various restrictions of freedom, drawing on biomedical principles (e.g. respect for autonomy, beneficence, nonmaleficence and justice) as well as more care-related factors such as the importance of relationships, solidarity, well-being and dignity.

We attempt to provide an overview of some of the main ethical arguments and dilemmas found in the literature on this topic and propose recommendations based on group reflection and discussion within the expert group. These are not definitive recommendations about which course of action or approach is always right as the right decision will depend on a range of factors including, first and foremost, the needs and wishes of the person with dementia but also of carers and healthcare professionals. As with previous reports, we hope that this publication will lead to further reflection on the issues covered at all levels from informal carers and healthcare professionals to policy makers and representatives of the legal system.

I would like to thank Dianne Gove, Chair of the working group, for carrying out the literature review and drafting the text. I would also like to express my gratitude to the members of the multidisciplinary working group who engaged in two full days of group discussion on these topics and developed over the space of a year the various drafts which led to this final report. The members of the group are (in alphabetical order): Antonio Burgueño Torijano, Eleanor Edmond, Brenda Frederiks, Chris Gastmans, Dianne Gove (Chair), Fabrice Gzil, Jan Killeen, Anna Maki-Petjä-Leinonen, James and Maureen McKillop, Marianna Siapera and Maria do Rosário Zincke dos Reis. The members of the working group, whose affiliations and titles can be found in section 1.2 of this report, were from a range of professional backgrounds including ethics, law, theology, medicine, disability, research, policy, mental capacity and psychology. We were also pleased to involve James McKillop who has dementia and Maureen McKillop who is his wife and carer.

I wish you an interesting read and hope that you will not hesitate to share your thoughts and reflections with us on any of the topics covered.

Heike von Lützu-Hohlbein
Chair
Alzheimer Europe



Introduction

1 Introduction

1.1 Background to this project

This document is the third report produced by Alzheimer Europe in collaboration with a team of experts in the framework of the European Dementia Ethics Network (EDEN), which was set up in 2009. This follows on from the work on the ethical issues linked to the use of assistive technology (AT) in 2010 and the ethical issues linked to dementia research in 2011.

A multidisciplinary working group was set up, which included a person with dementia and carers, as well as representatives from Alzheimer Associations and experts in different domains such as medicine, medical ethics, philosophy, psychology, law and disability. The group met twice within the year, each time for a full day, in order to discuss the various issues, comment on the drafts and formulate recommendations. Further discussion about the final document took place between members of the group by means of email.

The group had three specific objectives:

1. To provide an overview of past and current ethical debates on the topic of the restriction of freedom of people with dementia;
2. To explain its position;
3. To provide recommendations, where possible, on the topics covered.

These recommendations represent the views of the ethics working group at the time of publication, which were subsequently adopted by the board of Alzheimer Europe. They should not in any way be considered as binding on any individual or group.

1.2 Members of the working group

The members of the working group, to whom Alzheimer Europe is immensely grateful for developing these recommendations and contributing towards the position of Alzheimer Europe, are (in alphabetical order):

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Mr James McKillop, MBE, Scottish Dementia Working Group (SDWG) and Mrs Maureen McKillop, carer (Scotland, UK)

Ms Jan Killeen, Policy Consultant, Alzheimer Scotland (UK)

Ms Maria do Rosário Zincke dos Reis, Lawyer (Portugal)

Dr Marianna Siapera, MD, Greek Association of Alzheimer's disease and Related Disorders, (Greece)

1.3 Key concepts

1.3.1 Dementia

"Dementia" is the term used to describe a set of symptoms that include loss of memory, mood changes and problems with thinking, orientation, comprehension, calculation, learning capacity, language and judgement. It is an umbrella term which describes the symptoms that occur when the brain is damaged as a result of one or more diseases and conditions. The ICD-10¹ definition of dementia is one of the two most commonly used classification systems for diagnosing dementia (the other being the DSM-IV²). According to the ICD-10, for a diagnosis of dementia to be made, the memory and intellectual impairments must be sufficient in nature to cause significant social and occupational impairment and not occur solely during a state of delirium (Grabowski and Damasio, 2004).

Dementia is usually a progressive or chronic condition. This means that the symptoms tend to develop slowly but steadily over several years. It is not a natural part of growing old even though the prevalence of dementia is higher amongst older people. There are over a hundred different types of dementia. The most common are Alzheimer's disease (AD), vascular dementia and dementia with Lewy bodies. Often, the type of dementia is referred to by the condition which caused it although a person may actually be affected by more than one type of dementia.

1 The International Statistical Classification of Diseases and Health Related Problems (10th revision) of the World Health Organisation.

2 The fourth version of the Diagnostic and Statistical Manual of Mental Disorders of the American Psychiatric Association.

Although the main symptoms of dementia are cognitive (i.e. linked to the functioning of the brain), dementia has a social, physical and psychological impact on people. Sometimes, the reactions and behaviour of people with dementia are mistakenly attributed to changes in their brains when in effect, they are responding appropriately to frustration, worry, events or the attitudes and behaviour of other people. Nevertheless, certain behaviour and reactions are often referred to globally as behavioural and psychological symptoms of dementia (BPSD). According to a 1996 consensus statement from the International Psychogeriatric Association, the term BPSD is used to define symptoms of disturbed perception, thought content, mood or behaviour that frequently occur in patients with dementia (Kozman et al. 2006). This is very important to the debate on restrictions of freedom because BPSD are stressful for people with dementia and contribute considerably towards caregiver strain (Black and Almeida, 2004). This is often a key factor in decisions to institutionalise people with dementia (Banerjee, 2009), which has consequences for their freedom. BPSD often remain problematic for professional carers and may increase the likelihood of restraint being used, which represents a further restriction of freedom.

With regard to the Diagnostic and Statistical Manual of Mental Disorders (DSM) mentioned earlier, there are currently plans to implement a new classification of various types of dementia. The new classification system will be known as DSM-5 and will result in some of the terms currently being used changing. Although the DSM classification is American, it is likely to be used in many countries or for specific purposes. The terms used in this report may therefore gradually become less common in some countries depending on the classification system used.

Also, new criteria for mild cognitive impairment (MCI) have recently been developed (Morris, 2012) which introduce possible functional problems to MCI. This blurs the distinction between mild AD and MCI. Diagnosis would therefore be difficult at that stage and to overcome this problem, some scientists suggest the need to consider MCI as a pre-stage of dementia. However, MCI is a state of cognitive decline which falls somewhere between “normality” and dementia and not a disease *per se* (Gauthier et al., 2006). Dubois and Albert (2004) question the usefulness in clinical practice of labelling a syndrome with multiple causes rather than determining the underlying disease. Not everyone with MCI will develop dementia because there are several possible causes of MCI. Some may be linked to dementia, others not. Some people with cognitive complaints do not fulfil the criteria for MCI but eventually do develop dementia (Nunez et al., 2010). As this is not very helpful, the concept of prodromal AD was introduced in 2000 to specifically describe the type of MCI which leads to AD (Dubois, 2000).

The term “prodromal AD” is used to describe an extremely early stage of dementia characterised by an early symptom or set of symptoms which might indicate the start of the condition but before specific symptoms occur (Dubois et al., 2010). The term preclinical Alzheimer’s disease describes the early phases of the disease when accurate clinical diagnosis is not possible because symptoms of the disease have not yet appeared (Sperling et al., 2011). The value of labelling asymptomatic at-risk people as having a “disease”

when some of them may never develop any overt clinical signs or symptoms has been questioned (Giaccone et al., 2011 writing in the *Neurology Lancet* in the name of the BrainNet Europe Consortium).

The scope of this report is intended to cover people of any age who have any form of dementia, either having been diagnosed with dementia or having the clinical signs and symptoms of dementia but no diagnosis. Dementia is most common in older people and is considered an organic form of mental disorder. As will be explained in the section on reasonable accommodation, dementia is also a disability. Debates in related domains, which are relevant to a consideration of the ethical issues linked to restrictions of freedom of people with dementia, may well use terms other than dementia such as disability, cognitive impairment, mental disorder or older people. When referring to debates or research in those domains, such terminology will be used. As some debates or studies are linked to a particular type of dementia, such as Alzheimer's disease, the same terms will be used in this report when commenting on them. In some cases, however, the points being made may also apply to people with other types of dementia.

1.3.2 Capacity

Mental capacity and legal competence

When we talk about capacity, we generally mean the ability to do something or to understand something. However, this necessitates several other skills such as understanding relevant information, weighing up the pros and cons of possible decisions, considering the possible consequences of making or not making a decision, and making, remembering and communicating the decision (Alzheimer Scotland, 2012).

There is not one overall capacity but several such as the capacity to manage financial or administrative matters, the capacity to get dressed or washed, the capacity to take part in a conversation and so on. When a person lacks capacity with regard to a certain area of life, it may affect other areas of life and even certain legal rights such as the right to make a will, to marry or to make a binding contract. However, it is important to emphasise that people do not lose their capacities all at once or in a specific order. Some people lose the ability to carry out tasks alone but with a little help can manage. A number of factors can also affect a person's capacity to fulfil a specific task. Capacity is task specific and may be influenced by internal and external factors (such as lighting, tiredness, the time of day, the people involved and the nature of the task or decision). Capacity should therefore always be considered in relation to a specific task at a specific time and in specific circumstances. It should not be assessed on a once and for all basis and it should not be presumed that a person with dementia lacks capacity simply because they have dementia.

Mental capacity is one form of capacity. It is the term often used to describe the capacity to make reasoned and informed decisions (i.e. based on a full understanding of the relevant issues having been given the necessary information, having weighed up the pros and cons of various possible decisions and being able to communicate that decision).

Legal competence (or legal capacity) is the term often used to describe a state in which a person is considered as having the necessary and sufficient capacity to carry out a specific task (e.g. the capacity to drive or to make a will). It represents legal recognition of the validity of a person's choice. However, it is sometimes assessed on a once and for all basis (e.g. in the context of establishing guardianship measures in some countries) and may result in the permanent loss of certain rights (e.g. the right to drive, make a will, marry or consent to medical treatment). This is not very common nowadays but nevertheless the decision to declare a person legally incompetent or lacking legal capacity even in relation to a specific task tends to be made on a one-off decision basis after an assessment in which the person is considered to have failed to reach a threshold of competence for that task.

Although many people under the age of 18 may have the mental capacity to make medical decisions, they are not considered legally competent to do so (DuBois, 2008). The decision to declare a person with dementia legally incompetent or lacking legal capacity in a certain domain should be based on the finding that they lack capacity (usually mental capacity) in relation to that task.

➤ Alzheimer Europe is opposed to the practice of declaring people with dementia completely legally incompetent.

Self-determination and substitute or supported decision making

The observation that a person with dementia lacks the capacity to make a particular decision raises the question of how necessary decisions should be made. When a person lacks capacity, they lack the ability to exercise self-determination (i.e. to make decisions based on what they feel is best for them). The right or freedom to make decisions about one's own life underlies practically all the topics addressed in this report and will therefore not be addressed separately. However, it is important to also consider what happens when a person lacks the ability to make decisions on their own.

All member states of the European Union have a system of guardianship whereby a person can be appointed to make decisions on behalf of someone who lacks the ability to do so (i.e. substitute or proxy decision making). Several terms are used to describe the person with that responsibility such as guardian, tutor, curator, legal representative or mentor. In some countries, different types of proxy decision maker co-exist but the scope and extent of their responsibilities differ. Increasingly, proxy decision makers are expected and even obliged to involve the person with incapacity in the decision-making process. It is sometimes explicitly stated in guardianship or patients' rights legislation that this includes taking into consideration previously expressed wishes (e.g. as known or expressed in an advance directive). This is supported by article 12 of the United Nations Convention on the Rights of People with Disabilities (UNCRPD) (2006) particularly paragraph 3 which emphasises the need to provide sufficient support to enable people with disabilities to make decisions and paragraph 4 which emphasises the importance of respecting the person's wishes and preferences even if they are unable to make decisions:

3. [...] Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
4. [...] Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.

In Ireland, Amnesty International Ireland and the Centre for Disability Law and Policy, National University of Ireland, Galway (2012) recently teamed up with 15 organisations to write a set of key principles that the new capacity law of Ireland should reflect. In this document, they emphasise that everyone has the right to make decisions about their life but recognise that different levels of support may be required depending on each person's remaining capacities.

The first level of support is that which is necessary for people who have the ability to make a decision with only minimal support (e.g. larger print). The second level of support involves a trusted person providing support to the person to make a decision (i.e. supported decision making). The third level, known as "facilitated decision making", involves a representative determining what the person would want but where their preferences or wishes are not necessarily known. Consequently, this is only suggested as a last resort. The emphasis on giving people the support they need to make decisions rather than having other people decide on their behalf is in keeping with article 12 of the United Convention on the Rights of People with Disabilities which aims to protect people's right to make decisions about their own lives and the principle of "reasonable accommodation"³ (see section 2.1.1 for more details about this).

Further information about the requirements for the effective development and implementation of supported decision making can be found at:

http://www.amnesty.ie/sites/default/files/report/2012/04/PRINCIPLES_WEB.pdf

Another interesting document for further information and practical guidance on supported decision making has been produced by Jan Killeen of Alzheimer Scotland (2012) and funded by the Nuffield Council. It can be downloaded at:

<http://dementiascotland.org/news/files/Dementia-Making-Decisions.pdf>

³ Article 2 of the CRPD: 'Reasonable accommodation' means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to people with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms; ..."

These two publications also contain a number of recommendations on the assessment of capacity and the practice of supported decision making.

- The principles of reasonable accommodation and supported decision making are promoted in this report on the ethical issues linked to restrictions of freedom of people with dementia

1.3.3 Freedom and liberty

The terms “liberty” and “freedom” are sometimes used interchangeably and this can be detected in the origin and definition of the words. Liberty, for example, stems from the Latin *libertatem* which means “freedom” or the “condition of a free man” in the sense of being free from the interference of the government and other restrictions on personal freedom. Freedom stems from the Old English *freodom* which means “state of free will, charter or deliverance” (Emelda, 2011). According to Carter (2012), the use of either term is merely a question of style despite a few recent attempts to distinguish between the two. In some languages there is only one term such as in French (*liberté*) and German (*Freiheit*). These terms should therefore be considered as synonymous throughout this text. In some cases, the choice of term used is a matter of style, whereas in others it reflects the terminology used by various authors.

Liberty has been associated with having the right and power to believe, act and express oneself as one chooses and of being free from restriction. This is sometimes expressed in terms of positive liberty which involves the freedom or possibility to act based on the presence of something (such as control, self-mastery and self-determination) or negative liberty which emphasises freedom to act without obstruction from other people or the state, based on an absence of something (such as barriers, constraints, laws and outside interference) (Berlin, 1969). The promotion of negative liberty in a given domain would therefore involve the creation of an environment or sphere of action which was free from obstacles and in some cases from State control. The promotion of positive liberty would involve addressing factors which affect the ability of individuals or groups to act autonomously. This is therefore more closely related to capacity, choice and free will.

Another distinction that has been made is between natural and social freedom. Rousseau, for example, described a basic sort of personal or natural freedom which stems from the natural state of instincts and selfishness. Social freedom, on the other hand, was described as the civil or moral freedom, which is based on entering into a social contract and accepting a general will (Amezquita, 1992). Locke did not agree with Rousseau that people’s natural freedom should be abandoned but agreed that the social freedom of adhering to a general will necessitated complete involvement. Clearly, blind or unquestioning adherence to the general will does not constitute freedom. As an active citizen rather than a passive subject, people are free to challenge the ethical justification for laws and practices in society, which govern their lives or those of their relatives, friends and fellow citizens. Such blind obedience would not reflect an obligation of the social contract but an evasion of one’s duties as a citizen (Affeldt, 1999 cited in Chappell, 2005). Yet, some practices and laws exclude or rule out the participation of certain members of

society (e.g. by denying them the right to vote or failing to take their views into account) and in some cases by geographically distancing them from the rest of society.

There are also psychological or spiritual aspects to freedom. Viktor Frankl, a psychiatrist and holocaust survivor, distinguished between freedom based on external factors and a kind of inner freedom based on the freedom to choose one's attitude and reaction to whatever situation or condition one finds oneself in. He suggested that this internal freedom persists even when physical freedom has been taken away and when every aspect of one's life and even body is controlled by others. This is a kind of freedom which others cannot control but neither can it be guaranteed as it represents a personal approach to life.

"We, who lived in concentration camps, can remember the men who walked through the huts of others, giving away their last piece of bread. They may have been few in number, but they offer sufficient proof that everything can be taken away from a man but one thing: the last of the human freedoms--to choose one's attitude in any given set of circumstances, to choose one's own way." (Viktor Frankl, 1984, p.86)

Nevertheless, in the case of dementia, such freedom may become difficult to express due to cognitive difficulties or may be difficult for others to interpret or recognise. Further difficulties linked to the exercise and expression of inner freedom were expressed by Erich Fromm, a psychoanalyst and humanistic philosopher who, like Frankl, was also Jewish but who fled during the Nazi occupation. He described the acceptance and expression of freedom (in the sense of free will) as being healthy and drew attention to defence mechanisms which people use based on their fear of freedom (Fromm, 1991).

1.3.4 Restrictions or deprivation of freedom

Opinions about what constitutes a restriction of liberty depend on definitions. Such definitions are usually made on the basis of perceptions which are shared within particular cultures and come to be formally or informally accepted. Different definitions of the restriction of freedom are used in different contexts or for different purposes. Broad, everyday definitions of the restriction of freedom might emphasise the prevention of a person from doing what they appear to want to do. This might, for example, cover preventing a person from accessing or leaving a room, defined space or building, forbidding certain actions, forcing or putting pressure on someone to do something that they do not want to do, denying them the right to make certain decisions. Restrictions are not only imposed on people by the state or in the context of residential care; a person's freedom may be restricted by any other person and by any means in their own home too.

Narrower definitions are sometimes used, for example in scientific studies, and can be useful when it is important to count instances of restrictions of freedom which meet the defined criteria (Qureshi, 2009). A narrow definition of the restriction of freedom might focus on confinement of a resident to a room or area for a specified period of time, or preventing a person from leaving the nursing home. This would exclude many other forms of restriction of freedom but would make it possible to compare instances

of such restrictions with regard to specific criteria such as male and female residents or geographical location provided that such information had also been collected.

There are also legal definitions which may change over time as attitudes towards restrictions of liberty and practices change, and as new means of restraint are developed. The Austrian federal law on the protection of personal freedom during stays in homes and other care institutions (known as the Heimaufenthaltsgesetz) recently added electronic means of restraint to its definition of restrictions of freedom (Niemeijer, 2010). This suggests that means of restraint are considered as a form of restriction of freedom. Definitions of restraint are addressed separately below. Legislative changes often take time and in the period leading up to the change, people may lack adequate protection. Furthermore, many people with dementia who live in care homes or in their own homes have their freedom restricted but such acts are not legally recognised as restrictions of freedom. Some practices, which are widespread or common, are not even recognised as restrictions of freedom or as being unethical.

With regard to definitions, the difference between restrictions of freedom and the deprivation of freedom is also unclear. There is legislation in every member state of the European Union which lays down the conditions for the lawful deprivation of a person's liberty. These laws are fairly detailed but tend to be restricted to the compulsory detention of a person with a mental disorder in an institution or establishment for a set period of time for treatment or in the interests of their safety and/or that of other people. A variety of terms are used depending on the country which if translated might be involuntary or compulsory "detention" or "internment" or the restriction or deprivation of liberty or freedom. Apart from these laws, a clear definition of deprivation of freedom is often lacking.

In the *HL v. UK* case, which is discussed in section 2.1.2, the European Court of Human Rights made the following distinction between the restriction of liberty and the deprivation of liberty:

*"The distinction between a deprivation of, and restriction upon, liberty is merely one of degree or intensity and not one of nature or substance"*⁴.

This suggests a continuum with minor restrictions of liberty at one end, gradually becoming more restrictive and with severe restrictions, defined as deprivation of liberty, at the opposite end. The issue is not merely one of the duration of the measure or the size of the area to which a person is restricted. It can also be a matter of a high level of control being exercised over a person's movements (Cole, 2009). However, there are no criteria to measure the degree or intensity of the restriction. According to Cairns, Richardson and Hotopf (2010), the boundaries between lawful restrictions of liberty and the deprivation of liberty remain blurred. They further point out that with regard to definitions of deprivation of liberty, there is a lack of clarity as to what constitutes an objection

4 *HL v. United Kingdom* (2005) 40 EHRR 437

to the measure. In another case involving DE and JE v. Surrey County Council⁵, the Joint Committee on Human Rights favoured a view of the deprivation of liberty as consisting of a person not being free to leave rather than of having their freedom within an institutional setting curtailed (Cairns et al., 2010). After the Bournemouth case (see section 2.1.2), new legislation (known as the “Deprivation of Liberty Safeguards – DOLS) was introduced in England to provide better safeguards for people who are cared for in care homes and hospitals, and have been assessed as lacking capacity (Wigan Council, 2012). The application of the DOLS has been consistently problematic due to the wide range of administrative and judicial interpretations of “deprivation of liberty”⁶.

There is perhaps a tendency to consider restrictions of freedom in relation to geographical/spatial restrictions (e.g. being held against one’s will in a certain place or having one’s physical actions and movement restricted). The scope of this project extends to a reflection on the ethical issues linked to restrictions of freedom to live one’s own life without unjustified interference and to play an active role in society. We recognise the very close relationship between freedom and civil or human rights in that having certain rights represents the freedom to participate in society on an equal basis with other people and to live one’s life as one sees fit.

Whereas a broad definition of “restriction of freedom” allows recognition of the numerous ways in which people’s freedom is restricted, narrow definitions encourage precision when discussing these ways. In this report, we adopt a very broad definition of restrictions of freedom as being:

- The limitation of a person’s freedom of movement, action or choice, or of their participation in society.

Throughout the report, precision will be provided as to how this can be interpreted. Legislation is different in every country and does not necessarily reflect what is considered ethical at this moment in time. Opinions as to what is ethical may influence legislation but sometimes agreement that something is ethical (or unethical) only comes some time after a change in law. In this report, we may occasionally refer to legislation in order to provide background information about how various issues are addressed in society. However, we will not limit our position to what is or is not legal. Also, although guardianship is a legal measure designed to protect people with incapacity which tends to result in loss of freedom, this will not be addressed in this report but may be discussed in future work on proxy decision making.

This report also reflects a human rights approach which recognises that personal freedom is an inherent human right independent of national laws and European conventions. As such rights apply regardless of distinctions such as age, race, gender, language

⁵ JE and DE v. Surrey County Council and EW (2006) EWHC 3495 (Fam)

⁶ For more details, please see the Care Quality Commission report (2011), http://www.cqc.org.uk/sites/default/files/media/documents/dols_report_2010-11_-_summary_-_foundry.pdf

or religion. They are relevant to the principles of justice and equity. Consequently, any measures which serve to restrict a person's freedom in any way must be justifiable on non-discriminatory grounds (i.e. not on discriminatory categories such as age or having dementia).

1.3.5 Restraint

The ways in which freedom is restricted may be broadly defined as measures or means of restraint. Examples include physical and psychological restraint as well as the use of mechanical, chemical, environmental, electronic and other means or devices. Coercive measures could also be considered as a means of restraint as they restrict a person's freedom to choose not to do something. Broad definitions of restraint include the following:

- All (physical and verbal) measures which restrict the freedom of clients (Health Care Inspectorate, the Netherlands, 2008 cited in Frederiks, 2012)
- [...] anything which interferes with or stops a resident from doing what they appear to want to do (Clarke and Bright, 2002).
- [...] when the planned or unplanned, conscious or unconscious actions of care staff prevent a resident or patient from doing what he or she wishes to do and as a result place limits on his or her freedom (Mental Welfare Commission for Scotland, 2006).

The Dutch Care and Coercion Bill distinguishes between different degrees of restraint covering not only severe examples such as physical restraint, seclusion and the covert administration of medication, but also electronic surveillance devices and all kinds of subtle forms of coercion. Examples of the latter include influencing clients or forbidding them to visit a friend, watch their favourite series on television or have a cigarette (Frederiks, 2012).

In research settings, more precise definitions are sometimes used, especially with regard to physical restraint:

"...any artificial physical limitation applied to restrict patients' mobility (i.e. straps, bands, sheets or pyjamas)." (Weiner, Tabak and Bergman, 2003)

"any device, material or equipment attached to or near a person's body and which cannot be controlled or easily removed by the person and which deliberately prevents or is deliberately intended to prevent a person's free body movement to a position of choice and/or a person's normal access to their body." – (Retsas et al. 1998 in Gastmans and Milisen),

The second definition, which according to Qureshi (2009) is based on US regulations, provides a lot of detail about a single form of restraint and includes certain criteria which might also apply to other forms of restraint such as deliberate intention to restrain, "normal" access to one's body (which might be based on value judgements) and the degree of difficulty to free oneself. This enables examples of restraint to be counted and compared. It also creates more criteria to be fulfilled before a measure qualifies as physical restraint.

Narrow definitions run the risk of being too restrictive and may amount to “all or nothing” approaches in which there is no possibility to distinguish between varying degrees of restraint. A person is either restrained or not restrained. As discussed in relation to the restriction or deprivation of a person’s freedom, the degree and extent of restriction is important. Such definitions may also rule out certain forms of restraint simply by the terminology used. Rules and regulations, psychological measures and certain coercive tactics might not be considered as restraint depending on the definition used. This could result in people subjected to their use not being adequately protected.

The use of restraint, particularly on frail, older people with dementia, is generally considered unethical or harmful and is rarely justifiable. However, there may be exceptional cases when this is not so and it could be considered lawful and/or ethically justifiable. To avoid confusion, it is preferable to attribute a neutral meaning to the term “restraint” (Commission for Social Care Inspection, 2007) and then to consider whether or not its use is ethical. This means that a definition of restraint should preferably not include a reference to deliberate prevention or a deliberate intention to prevent or restrict freedom of movement.

In some countries, such as England, the law specifically addresses the use of restraint, outlining what does and does not constitute restraint and establishing conditions governing the lawful use of restraint (Mental Capacity Act, 2005). The Human Rights Act of 1998 requires care providers to take preventative measures to ensure that people’s rights are respected and this has implications for the use of physical and chemical restraint as well as for respect for privacy (Commission for Social Care Inspection, 2007). Restraint is defined in Section 6 of the Mental Capacity Act 2005 (of England) as:

- the use or threat of force to secure the doing of an act that the individual resists; or
- the restriction of the individual’s liberty whether that individual resists or not

It is further stated that the measure must be in the person’s best interests, necessary in order to prevent harm, a proportionate response to the likelihood of the person suffering harm and proportionate to the seriousness of that harm.

The issue of restraint has recently attracted considerable attention in the Netherlands following a public outcry about the treatment of a young man with behavioural problems who was mechanically restrained on a 24 hour, daily basis in a room with no windows. This lasted for three years (Frederiks, 2011). In addition, the Netherlands has recently added electronic restraint to its legal definition of restraint. This is also the case in Austria.

The Finnish Mental Health Act (No. 1116) of 1990 addresses the use of coercive measures, abuse and the unlawful deprivation of freedom (which includes the use of restraint) (Mäki-Petäjä-Leinonen, 2011). However, this is only applicable in the context of involuntary treatment in psychiatric hospitals or wards. People with dementia are usually treated elsewhere e.g. in nursing homes where restraint is sometimes used. There is still no adequate legislation in Finland covering the use of restraint in ordinary hospi-

tals or nursing homes. For this reason, the National Supervisory Authority for Welfare and Health, known as “Valvira”, has produced guidelines (“*Use of restraint for patients*”). According to the Valvira, the use of restraint is only permitted to prevent serious harm to a patient’s health or safety. It further states that:

- a doctor must make a written/documented statement of his/her decision concerning the use of restraint for a patient.
- the need for restraint has to be evaluated regularly.
- the proper equipment must be used in accordance with guidelines on the use of restraint.

In 2010, the Ministry of Social Affairs and Health established a working group whose aim was to assemble the provisions relating to the deprivation of liberty and self-determination of all patients/clients of social and welfare, within the same act if possible. The reform of the legislation specifically addresses the deprivation of liberty in the care of people with mental disabilities and dementia. Its goal is also to strengthen multidisciplinary co-operation and the availability and development of services in such a way as to lessen the need to limit liberty and self-determination.

Most definitions of restraint focus on its use in the professional care setting rather than in people’s private homes. Clearly, this is influenced by the examples selected and quoted and the fact that they are derived from publications and legal provisions relating to residential care. However, apart from definitions used in research which do not always make this distinction (as the populations selected for study are in any case mainly from care homes), most debates about restraint focus on the residential care setting.

The use of restraint in people’s own homes is not as well documented and not as easy to monitor. If detected, it might be considered as abuse rather than restraint and clearly, the wrongful use of restraint does amount to abuse. Abuse of elderly people has been defined as:

“A single or repeated act or lack of appropriate action, occurring within any relationship where there is an expectation of trust, which causes harm or distress to an older person.” (World Health Organisation, 2012).

Abuse does not only happen to older people with dementia. Younger people with dementia may also be subjected to restraint, in some cases perhaps more so (e.g. if they have aggressive behaviour) as they may be perceived as more physically threatening than an older, frailer person. However, some national laws particularly mention old age as an aggravating factor in accusations of abuse.

Attitudes towards the use of restraint within the home can perhaps be likened to those towards domestic violence between couples in the not too distant past when it was considered a private matter to be sorted out between the parties concerned, with the state only intervening in extreme cases. In this report, many of the studies cited are set in the residential care setting and certain issues discussed in this report may be more appli-

cable to that setting than to the home setting. However, the scope of this report is the restriction of freedom of people with dementia in their homes (or where they reside in another person's home), in residential care settings and within society in general.

In this report, we will adopt a broad definition of restraint as being:

- Any method, device, substance or procedure which restricts a person's freedom of movement in the private or health and social care setting, irrespective of the intent to restrain.

This definition covers physical, chemical, psychological, electronic and environmental restraint as well as coercive measures which restrict freedom of movement. Further specification will be provided in the relevant sections.

1.3.6 Ethical issues

What do we mean by "ethics"?

Broadly speaking, ethics is a branch of philosophy which seeks to address issues related to concepts of right and wrong. It is therefore closely linked to morality in that it is about what morally ought to be the case rather than how things necessarily are. It is about how we ought to act towards one another and covers numerous decisions we make in everyday life, as well as decisions with implications for life or death (Mattiasson and Hemberg, 1998). 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. People are therefore sometimes confronted with an ethical dilemma. This has been described as a situation "with conflict between two or more ethical principles and each solution may contain unpleasant outcomes for one or more involved parties" (Crisham, 1996 in Yamamoto and Aso, 2009). It may be necessary to decide on a particular course of action rather than another and in so doing to give greater weight to certain moral concerns at the expense of others.

Nevertheless, according to Chan (2001), any decision taken about a moral problem should be based on reasoning and require justification. People who take decisions or act in a way which has implications for the freedom of people with dementia do not necessarily need to have expert knowledge about ethical theories. However, they should be aware of the ethical issues at stake and be able to reflect on them in order to determine what is right or wrong in a particular situation. This is essential when the person whose freedom risks being restricted lacks the capacity to make decisions. They may be giving

clear signs that they are opposed to a restrictive measure, other people may be trying to decide on their behalf, some arguing in favour of a particular measure being used, others against its use. When making decisions at home, conflict may arise between the needs and desires of different members of the family. Even in situations where the person with dementia has sufficient capacity to make particular decisions, there is a risk of other people taking decisions which do not correspond to their wishes or well-being based on facility (i.e. for the ease or convenience of other people) or a lack of understanding about dementia.

Informal and professional carers come from a wide range of backgrounds and have a wide range of personalities and characters. For some, becoming a professional carer of people with dementia was a deliberate choice reflecting a desire and interest in caring for people with dementia. For others, it is perhaps “just a job” and they may have little training or understanding about dementia. Informal carers (i.e. relatives and close friends) may provide care out of dedication, love or a sense of duty. Some may have just drifted into care and may feel resentment, that they had no choice. Some people do not consider themselves as “carers” but the decisions they make may have an impact on the freedom of people with dementia (e.g. with regard to voting, the way of life within care homes or decisions to move a person with dementia into residential care). People are not ethical or unethical *per se* but may behave ethically or unethically towards people with dementia. Certain personality traits, such as integrity, trustworthiness and honesty, may increase the likelihood of people behaving ethically or unethically but sometimes unethical conduct may be linked to lack of knowledge or awareness. It is essential that people who make decisions affecting the lives, in particular the freedom, of people with dementia have a sufficient understanding about dementia and, for decisions to be ethical, that they are aware of and able to reflect on ethical issues.

What are the different kinds of ethical theories?

There are different types of ethics. One of these, namely “applied ethics”, applies ethical theories to real life situations which matter to people. In some cases, the issue at stake may be a matter of principle or well-being, in others it may be a matter of life or death. In this report, we are interested in ethical issues relating to restrictions of freedom. The different theories which might be considered or partly guide ethical decision making are briefly described in this section. This is not a comprehensive review. As a group, we do not favour a particular theory over another. Each has its own strengths and weaknesses and may appeal to each person’s values and logic more than another theory. Those which a person finds meaningful may influence the way they apply concepts to real-life situations.

Some approaches to ethics focus on the outcome. This might involve judging whether the consequences of the act are good or bad (Noble-Adams, 1999) or what the best outcome would be for the greatest number of people (Peach, 1995 in Aita and Richer, 2005). In the utilitarian approach, for example, which was formulated by Bentham and Mill in the 19th century, actions are considered as right if they are likely to promote the greatest happiness for the greatest number of people. Actions likely to result in the opposite

would be considered as “wrong”. Evaluations of the various outcomes tend to focus on pain and pleasure. However, as pointed out by Petrini (2011), this approach only considers the amount of good and not the way in which it is distributed. Furthermore, there may be more than one issue at stake and it would be difficult to measure maximum happiness. Maximising happiness may even conflict with other values such as justice, fairness, solidarity and honesty. In addition, there are a lot of different interpretations as to the value of different outcomes as well as different motivations driving action and different opinions about the importance of particular ethical principles.

Virtue ethics, on the other hand, 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). Beauchamp and Childress (2008) considered the relevance and desirability of five virtues for health professionals. These included compassion, discernment, trustworthiness, integrity and conscientiousness. They also considered the ethics of care which focuses on relationships involving care, responsibility, trust, fidelity and sensitivity with particular reference to the doctor-patient relationship.

Other theorists consider whether the nature of an act is right or wrong irrespective of the consequences. Something is believed to be good if it is consistent with moral rules and principles. This is often described as a deontological theory and a classic example is Kant’s theory. He stated that as man⁷ is a moral agent, he is responsible for his actions. They are intrinsically right or wrong. However, Beauchamp and Childress (2008) define deontological theory as being that some features of actions rather than *or in addition* to consequences make actions right or wrong. Critics argue that the consequences of actions should not be ignored (Petrini, 2011). Deontologists typically have sets of standards which they use to guide them in their actions and in making decisions that they consider 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 pre-occupied with their own interests (State of Victoria, 2006).

The best known ethical principles in the biomedical field are perhaps those inspired by Beauchamp and Childress (2008, p.12) which are: 1. Respect for autonomy, 2. Nonmaleficence, 3. Beneficence and 4. Justice. As will be seen in this report, they are not the only principles of relevance to the ethical issues linked to restrictions of freedom. However, as frequent reference is made to such principles within the context of ethical decision making in relation to people with dementia, they are briefly explained below.

⁷ “man” should be understood as meaning human beings (i.e. men and women). The term is used here simply to reflect the language usage at the time the statement was made.

Autonomy is traditionally considered as being linked to self-determination and exercising choice. For this reason, consent 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 Beauchamp and Childress (2008):

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.

The capacity-based approach to autonomy, with its emphasis on rationality and being free to choose, has been challenged by Agich (2003) who suggests that “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 further suggests that with people who are dependent on others, or faced with obstacles due to illness or disability, autonomy may be expressed through attempts to adapt and cope irrespective of whether reasons for actions or choice can be rationally explained. A richer concept of autonomy has also been proposed by the Nuffield Council on Bioethics (2009) which suggests that autonomy should also be considered as the way that a person expresses their sense of self, in their relationships and in their values and preferences.

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), for example, who combined the two principles under the term beneficence, described four main goals, namely not to inflict evil or harm (what is bad), to prevent evil or harm, to remove evil, and to do or promote good (quoted in Dawkins, 1998, p.10). In relation to people with dementia, these two principles are often reflected in discussions about the need to protect the physical safety and integrity of people with dementia.

In health care 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). 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). Finally, Perry, Beyer and Holm (2009) suggest that respecting the principle of justice requires that the needs of the individual be balanced with those of the wider community.

Some people believe that ethical principles are universal (ethical universalism) whereas others take the view that such principles are related to a specific culture or individual choice (ethical particularism) and hence not generalisable to people with different cultural beliefs. The latter has also been referred to as communitarian ethics which maintains

that moral thinking has its origins in the historical traditions of particular communities and that consequently, it is a cultural rather than abstract concept in that communities share values, customs, institutions and interests (Petrini, 2011). However, many societies or geographical areas are fairly multi-cultural nowadays with people from different cultural backgrounds living together, sharing certain values and differing on others. Petrini (2011) warns against an over-emphasis on communitarian ethics which might result in a “tyranny of the majority” whereby the majority defines what is beneficial, morally right or “a good life”, and which may result in an unfair outcome for some groups of people (Petrini, 2011).

Contrary to approaches which focus on the majority or the community, “personalism” strives to achieve common good by promoting and enhancing the good of the individual guided by values such as respect for life, sociality and solidarity, and responsibility (Petrini, 2011).

Care ethics

With care ethics, the emphasis is not on the act or on consent to the act, nor is it on the decision. Rather, the emphasis is on the care relationship/process, on being receptive to what happens to the person, on respect and trust (Mahieu and Gastmans, 2012). This is characterised by reciprocity. There is a relationship of trust whereby the person with dementia trusts another person/people to look after them. The necessity for such trust is partly based on the potential vulnerability of people with dementia and is dependent on handing over a certain degree of control to others. Carers therefore have a considerable responsibility for the well-being of the person with dementia and care ethics provides a framework within which to provide ethically acceptable and appropriate care to people with dementia. Concepts of relevance to care ethics also include dignity, singularity (focusing on the unique nature of each person), historicity (reflecting the historical dimension of human existence) and relationality (considering what is meaningful to each person in terms of their relationship to others). These issues are discussed in more detail in section 2.3.3 on sexuality and relationships.

Finally, when people make statements about ethical issues (such as “it is wrong to chemically restrain people with dementia”), how should they be understood? Four possibilities have been suggested, namely moral realism, subjectivism, emotivism and prescriptivism. In that order, expressions might be considered as a statement of a fact, a statement about how the person making the statement feels about a particular issue, an actual expression of that feeling or an instruction (or alternatively prohibition) (BBC, 2012). In this report, we provide background information on numerous practices and try to provide a balanced explanation about all the issues at stake and different arguments. At the end of each main section, however, we make recommendations. These should not be considered as “facts”, nor as expressions of emotions but as the opinion of the working group, as approved by Alzheimer Europe, as to what should or should not be done in a typical situation or in general. However, they cannot be considered, strictly speaking, as instructions or prohibitions as no two situations or people are the same. Those respon-

sible for making a decision about the restriction of liberty of a person with dementia must weigh up all the relevant issues and consult with everybody concerned, making every effort to involve the person with dementia in the decision-making process. Hopefully, this report and the recommendations will be helpful in that context. In most cases, the recommendations are more a question of principles to bear in mind when trying to come to an ethical decision.

1.4 Structure and layout of the report

Chapter 1 has provided background information about the project and a description of what we mean by some of the key terms used such as dementia, freedom and liberty, the restriction or deprivation of liberty, restraint and ethical issues. In the description of “ethical issues”, we explained that this involves applying ethical theories and principles to a specific issue. Our interest is in restrictions of liberty.

Chapter 2 divides issues relating to the restriction of liberty into four main topics:

1. Restriction of the freedom to choose one’s place of residence.
2. Freedom to live in the least restrictive environment.
3. Restriction of freedom to act according to individual attitudes, values and life-style preferences.
4. Restriction of the freedom to play an active role in society.

The first section of chapter 2 is about involuntary placement in an institution, hospital or care home. This involves the restriction of the liberty to continue living in one’s own home or with relatives or friends in a familiar environment. It is not just about preferences as to where one would like to live. On the contrary, it is about being legally obliged to leave one’s home, to give up a certain degree of independence and to adapt to community life (e.g. getting on with or tolerating other people and adhering to group living rules and practices). This section also covers placement in a home or institution on a “voluntary” basis. The main emphasis is on the process and implications of being admitted into residential care or an institution for care or into a hospital for necessary treatment. Issues related to life once there are addressed in the third section of chapter 2.

In the second section of chapter 2, we look at the various methods (other than legislation or voluntary agreement) which are used to restrict the liberty of people with dementia in their daily lives. The theme in this section is the freedom of people with dementia to live in the least restrictive environment. This covers topics such as physical restraint, chemical restraint and various psychological, environmental and electronic measures or devices. The use of assistive technology, such as surveillance devices and tracking devices, are only briefly addressed as this was the topic of the ethics working group in 2010.

In the third section, we consider how the freedom of people with dementia to live their lives according to their wishes is sometimes restricted. The focus is not on whether a

person has the capacity to make a decision but rather on respect for their individuality and right to self-expression. We therefore consider how a certain way of life and routines are sometimes imposed on people living in residential and semi-residential care settings which fail to take into consideration their individual preferences, habits and foibles and may be based on values they do not share. One of the topics covered is that of sexuality and relationships between and involving people with dementia.

The fourth section consists of a reflection on the ethical issues related to the restriction of the freedom to play an active role in society. Issues covered include voting, making decisions with legal implications (such as a will) and driving.

Each of the four sections provides background information about the topic covered and examines some of the main ethical issues related to that topic. A set of recommendations can be found at the end of each of the first three sections and at the end of each subsection in the last section of the report.

These are not definitive recommendations about which course of action or approach is always right. It is always necessary to reflect on each particular case rather than adopting a black and white or recipe-like approach. In many respects, the recommendations resemble principles to think about rather than actions to take. The right decision will depend on a range of factors including first and foremost the needs and wishes of the person with dementia but also of carers and healthcare professionals. Two overriding principles must also always be borne in mind, namely proportionality (i.e. that the decision is in keeping with the scale of the problem) and subsidiarity (i.e. that the least restrictive measure is applied first).





*Ethical issues linked
to restrictions of
freedom*

2 Ethical issues linked to restrictions of freedom

2.1 Restriction of the freedom to choose one's residence or place of stay

In this section, we address the ethical issues linked to restricting a person's freedom by obliging them to live or stay in a particular place or area either temporarily or permanently. This would include:

- involuntary detention in an institution, hospital or nursing home, either by means of a legal process or by more subtle means such as based on the person's failure to object
- placement in an institution, hospital or nursing home, or attendance at a day care centre based on failure to protest
- confinement to a particular area within a building or larger area.

The main ethical issues of relevance to these types of restriction of freedom are autonomy, nonmaleficence, justice (equity and non-discrimination), dignity and the fundamental human right to freedom. Often, restriction is achieved by means of various measures of restraint or coercion. These will be discussed in chapter 2.2.

2.1.1 Involuntary detention

Examining the grounds for involuntary detention

The legal justification for restricting the freedom or choice of residence of people with mental disorders is often based on the alleged danger they pose to themselves or others combined with proof that they have a mental disorder. Having a disability or mental disorder is not sufficient in itself to warrant involuntary detention. There must be a recognised danger in addition to the mental disorder. Article 14 of the UNCRPD states "the existence of a disability shall in no case justify a deprivation of liberty." This can be seen in numerous laws on involuntary detention. In the Belgian Law of 26 June 1990 on the Personal Protection of Mentally Disordered Persons, for example, it is stated:

"Failing any other suitable treatment, confinement measures may be taken in respect of a person with a mental disorder only if his or her condition so requires, either because he or she seriously endangers his or her own health and safety, or because he or she constitutes a serious threat to the life or integrity of others. Lack of adaptation to moral, social, religious or political or other values cannot of itself be considered as a mental disorder." (Chapter 1, article 2)

Legislation establishes the grounds for the legitimate deprivation of a person's freedom by proving a legal framework which defines the conditions to respect and the procedure to follow. This is sometimes stated in a country's Constitution. This is the case in Finland where under section 7 of the Constitution, it is stated that there shall be no interference in personal integrity or deprivation of liberty without legitimate grounds prescribed by an Act of Parliament. The European Convention on Human Rights (ECHR), describes everyone as having the right to liberty and security of person, and not being deprived of their liberty (article 5). However, paragraph 1(e) of the same article states that it is lawful

to detain people from certain groups, one of which is “persons of unsound mind”. In some countries, laws on involuntary detention also specify that the restriction of freedom must be in a particular place (e.g. in a hospital, a psychogeriatric ward or a psychiatric institution), which may differ from one country to the next and that it must be for the purpose of treatment. “Unsound mind” is not defined in the document. However, according to the European Agency for Fundamental Rights (FRA, 2011), in case law amounting to several hundred cases from the European Courts of Human Rights (ECtHR), numerous terms are used based on changing perceptions of mental illness and of progress in psychiatry. In national legislation, a whole range of terms is used for the now outdated term “unsound mind”. Specific reference is rarely made to dementia.

Having dementia and being perceived as a threat to oneself or others can therefore be sufficient criteria for the legal deprivation of freedom. In ethical terms, such deprivation of freedom affects a person’s self-determination based on the principles of beneficence and non-maleficence. In other words, a person is deprived of the right to make a decision in relation to their own life on the basis of the moral duty to promote their well-being and protect them from harm. It could be argued that people have the right to make unwise decisions even those which might endanger their own lives. Millions of people, who apparently have the necessary and relevant capacity, make unwise decisions and engage in risky behaviour every day. The standard liberal principle of letting people do what they want to do provided that it does not unfairly threaten the interests of others does not seem to extend to people with cognitive impairments (Wikler, 2010). People who do not lack capacity are therefore generally free to make unwise decisions and engage in risky behaviour whereas some others, including people with dementia, are not. The reason for this is perhaps because the former presumably understand what is at stake, can weigh up the pros and cons and take responsibility for the results, even those which turn out to be disastrous to their own well-being, health and even safety. In the case of dementia, depending on the individual, the stage of dementia and a range of associated factors, they may not be capable of such decision-making processes. In such cases, the right to make unwise decisions or behave in a way likely to threaten their own safety and well-being is no longer readily accepted. Depending on the circumstances, this may lead to a more protective approach. This could include the temporary or permanent restriction of their freedom to live in the place of their choice. The justification for the measure is therefore based on beneficence and nonmaleficence based on a perceived need to decide what is in the person’s best interests and to prevent them from coming to any harm. The issue of the right to take risks is discussed in more detail in section 2.2.

As the grounds for the restriction of liberty by means of involuntary detention include the person having a mental disorder and being in need of treatment or care, it is important to ensure that this is correctly assessed. A UK survey to ascertain if there is any consensus amongst psychiatrists, found that experts could not agree on what kinds of cases require the legal process for involuntary detention to be invoked. The study looked at 12 complex cases of people with dementia and acquired brain injury to judge what legal process had been followed and what legal processes experts thought should have been

followed. As a result the researchers recommended that safeguards be re-written in legislation. It was concluded that if experts do not agree then we cannot have confidence in the legislation and its guidelines (Killeen, 2012).

With regard to restrictions of freedom based on the perceived risk of the person with dementia causing significant harm to others, there is also a difference in approach in that people with dementia may be involuntarily interned in the absence of any criminal offence. People who do not have dementia would not have their freedom restricted unless they had committed a crime even though there are occasionally discussions about whether psychopaths and paedophiles should be involuntarily interned as a preventive measure (Ford, 1999 cited in Gostin, 2000). People with dementia, on the other hand, may have their freedom restricted based on the harm which they might possibly cause to others but have not yet caused and which may never occur. The restriction would therefore be a preventive measure and not a punitive measure.

The procedure for involuntary detention

In most countries there is a legal procedure to determine the conditions for involuntary detention during which people can defend themselves and appeal against the decision. However, it is presumably more difficult to defend oneself against an allegation that one might do something at some point in the future than against an allegation that one has already done something. The person whose freedom may be restricted has to defend themselves against other people's beliefs and presumptions as well as probability, perhaps but not necessarily accompanied by supporting evidence. Nevertheless, representing a danger to oneself or others and actually harming others are both legally accepted as justification for the possible deprivation of freedom.

The involuntary detention of a person with dementia who is a danger to him/herself or others and in need of care or treatment is, in ideal circumstances, based on medical reports from relevant experts such as psychiatrists. However, the initial measure to request involuntary detention may be dependent on health and social care professionals' ability to assess the capacity of a person with dementia in relation to a specific potentially dangerous situation. They may lack confidence in their ability to assess capacity and there may also be an absence of clear guidelines. This may result in them failing to make such assessments and in delays in dealing with the issue until the person's condition becomes severe or until a crisis occurs. In this way, the freedom of the person with dementia may be restricted far more than would have been the case, had measures been taken earlier to assess the person's capacity within the context of a specific situation (Killeen, 2012).

People with dementia may be at a disadvantage when it comes to defending themselves because of the ignorance, misinformation and stereotypes surrounding dementia. Judges and experts may be neutral and truly concerned to decide what is in the person's best interests. They may even recommend not to restrict the freedom of the person with dementia and argue in favour of their right to autonomy and independent living. However, there is an imbalance of power between people with dementia and

judges and mental health experts. The latter are considered qualified to make judgements about the capacity and best interests of people with dementia. The credibility and reliability of what people with dementia say in their defence is likely to be affected by those judgements. This constitutes an imbalance of power which may make it hard for people with dementia to defend themselves. It could be argued that medical experts do have the necessary expertise and can be trusted. Research suggests that this might not be the case. In the study mentioned earlier (reported by Killeen, 2012), psychiatrists could not reach consensus on the need for detention. This is worrying and suggests that people with dementia, might be having their freedom restricted lawfully but not justifiably. This means that they are being discriminated against on the basis of their condition in not being treated equitably. Other groups who experience a loss of their freedom presumably have a fair trial in which the justification for the deprivation of freedom is well established.

Is the restriction of freedom the right response to perceived threat?

In several countries, the justification for involuntary detention is that the person with a mental disorder who threatens their own safety or that of others is in need of treatment. Often the place in which the person can be involuntarily interned is a psychiatric institution or a psychiatric department within a hospital where the person can receive appropriate treatment for their mental disorder to render them safer.

The involuntary detention (e.g. in a hospital, psychogeriatric ward or psychiatric institution) of people with dementia in order to administer symptomatic treatment would, in many cases, be a disproportionate and even inappropriate response. Several studies have highlighted the inappropriate use of anti-psychotic, neuroleptic drugs to manage BPSD. This is addressed in more detail in the section on chemical restraint. However, the danger in the case of dementia is not always linked to such symptoms. It may be linked to other factors such as memory loss or confusion for which symptomatic treatment can also be provided within the community. A psychiatric hospital or even hospital ward would be unlikely to provide a suitable environment and skilled staff to ensure the well-being of people with dementia and could lead to further distress. Although people with dementia do sometimes pose a risk to themselves and others, it is unethical to deprive them of their freedom on the basis of inappropriate legislation and in inappropriate establishments for that reason.

It could be argued that the involuntary detention of people with dementia on the basis of a perceived threat to self or others is unethical as it does not respect the principle of justice which suggests that everyone should be treated fairly and equally. As mentioned in the previous section, other groups of people who threaten the well-being and safety of themselves or others are not involuntarily interned unless they actually cause harm. But in the case of mental disorders, including dementia, depending on the definitions applied, this often seems to be the only solution envisaged. Other solutions, which would enable people with dementia to continue living in the community, are possible but they require time, effort and money. These factors alone may be considered sufficient to rule out possible alternative solutions, which is unjust. According to the Commis-

sion for Social Justice (1994), it should be recognised that although not all inequalities are unjust, unjust inequalities should be reduced and where possible eliminated (cited in Akuffo, 2004).

Subsidiarity and “reasonable accommodation”

There are at least two competing ethical principles with regard to involuntary detention, namely respect for autonomy and beneficence. On the one hand, governments have a moral duty (and sometimes a legal obligation) to respect a person’s wishes to live in their own home. On the other hand, they have a moral duty to take the necessary measures to protect that person and third parties from harm. The question is “to what extent should they respect people’s wishes to remain at home?” The principles of subsidiarity and non-discrimination and the concept of reasonable accommodation must be considered. Whilst our interest in this section of the report is linked to where a person lives or is obliged to stay, the word “accommodation” (in the phrase “reasonable accommodation”) does not in this context refer to housing but rather to adaptations or adjustments aimed at meeting a recognised need.

The principle of subsidiarity requires that the option which is least restrictive of the person’s freedom be explored first: thus, voluntary detention must be considered as an option before involuntary detention.

A more proactive approach, consistent with the principle of subsidiarity would be to adopt the social model of disability endorsed by the United Nations Convention on the Rights of Persons with Disabilities of 2006 (CRPD) and focus in the first instance on what if any measures could be taken to keep the person in their own home.

In the preamble (e) to the CRPD, disability is recognised as

“resulting from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others,....

This represents a move away from the medical model of disability towards one which emphasises non-discrimination, equal opportunity and human rights. In article 1 of the CRPD, the responsibility of society is highlighted and a definition of disability provided which would include people with dementia:

“The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

Persons 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.”

Discrimination on the basis of disability or age (amongst other criteria) is forbidden in article 21 of the Charter of Fundamental Rights of the European Union (200/C 364/01).

Articles 25 and 26 also promote the recognition and rights of the elderly “to lead a life of dignity and independence and to participate in social and cultural life” and of people with disabilities “to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community”. These rights are echoed in article 15 (3) of the revised European Social Charter (Strasbourg, 1996), which promotes “the full social integration and participation in the life of the community in particular through measures, including technical aids, aiming to overcome barriers to communication and mobility and enabling access to transport, housing, cultural activities and leisure”. Article 23 of the revised European Social Charter further stipulates that appropriate measures should be taken to enable elderly people to remain full members of society for as long as possible, to choose their life-style freely, to lead independent lives in their familiar surroundings for as long as they wish and are able and for those living in institutions to participate in decisions concerning living conditions in the institution. These European Charters clearly promote the principles of non-discrimination and reasonable accommodation in relation to older people and people with disabilities.

Dementia is a disability and the necessity to make reasonable adjustments therefore also applies to dementia (Nuffield Council on Bioethics, 2009). Mental disorders, including dementia, are not always considered as disabilities even though the stigma associated with them may, in addition, be very disabling. Failure to acknowledge dementia as a potential disability may result in people with dementia not receiving the kind of protection and fair treatment envisaged in measures for people with disabilities (European Union Agency for Fundamental Rights (FRA), 2011). One of these measures is the duty to provide “reasonable accommodation”, with failure to do so being considered a form of “discrimination on the basis of disability”. These two terms are defined in article 2 of the CRPD as follows:

“Discrimination on the basis of disability’ means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation;

‘Reasonable accommodation’ means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to people with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms; ...”

Applying the principle of reasonable accommodation in everyday life means taking necessary steps to ensure that people with dementia feel comfortable carrying on with their usual activities such as going out to lunch, participating in church activities, doing voluntary work, going shopping and doing sport (Nuffield Council on Bioethics, 2009). Possible examples of reasonable accommodation include the following:

- 1: Ensuring that a person who is known to have dementia is not presented with lots of forms to sign and put under pressure to make hasty decisions. Even if the person has the relevant capacity, they may require assistance and it should be ensured that the right conditions are provided to enable them to make those decisions.
- 2: Ensuring that a person with dementia is not socially excluded or unnecessarily dependent on others based on difficulties travelling alone (e.g. working out fares for public transport or having the necessary pass, organising time and finding their way to the destination and back). In such cases, assistance or the provision of organised transport would enable the person to remain socially active and help prevent premature dependence on others.
- 3: Ensuring that the person with dementia is not denied the freedom to continue working. Reasonable accommodation might involve adapting or changing their tasks or providing necessary assistance.

The principle of reasonable accommodation is particularly relevant in the context of involuntary detention and consistent with the principle of subsidiarity and the obligation to explore the least restrictive alternative.

Providing real choice

The involuntary detention of people with dementia based on the fact that they have dementia (i.e. a disability), combined with the perceived danger they pose, represents exclusion and restriction on the basis of disability. It deprives them of the opportunity to exercise the fundamental human right to freedom which others enjoy. The deprivation of freedom of people with dementia may in some cases entail them being uprooted from their homes and from a familiar environment, moved away from friends and relatives and subjected to rules and regulations which do not correspond to their values or previous lifestyles. This may seem to be the only solution if there is no-one to keep a constant eye of them. However, the situation can be compared to that of toddlers (without suggesting that the people in the two groups are alike). Toddlers would have no-one to look after them and protect them from harm if society were not organised in such a way as to make it possible for at least one parent/carer to stay at home and look after them. Where this is not possible or desired, crèches are available and in some cases other relatives share the task of care. Western European society does not routinely have a system of handing over toddlers into long-term care to remain there until they no longer represent a threat to themselves or others. Where this does occur, it tends to be the exception (e.g. in the case of orphans and severely disabled children), when all else has failed and it is not a satisfactory solution. Moreover, there is a movement towards the deinstitutionalisation of all groups within society. The aim of this movement is to eventually replace institutions with community-based services so as to enable people with disabilities to live their lives in the way that they want to but with appropriate support and protection (Mansell et al., 2007).

The points made above only apply to involuntary detention as some people with dementia may be quite happy to move into long-term care institutions or homes. For some, this may provide them with a sense of security and even more social contact than they previ-

ously had. However, it is not always possible for people with dementia to obtain a place in a long-term care establishment. In some countries, waiting lists for places in affordable establishments are long (e.g. two years) and establishments offering good quality care are lacking. This means that many people with dementia living at home are not in a condition to do so, which raises the issue of nonmaleficence, neglect and the abandonment of people with dementia by society. It also raises questions about respect for the dignity and well-being of people with dementia and represents inequity in the provision of care.

On the other hand, it is unethical to oblige people to move into long-term care or be admitted against their will to establishments (especially those which are not suited to their needs) when necessary and appropriate modification and adjustments have not been made to their living situations so as to enable them to continue living in their own homes. Part of the definition of reasonable accommodation is that it should not impose a disproportionate or undue burden. This is fairly subjective. A consideration of what constitutes disproportionate or undue burden may differ depending on the group of people for whom reasonable accommodation might be applied. Taking the example of toddlers, State measures to ensure that toddlers can be cared for at home by at least one parent may seem a proportionate response to the need to protect their safety and well-being. For people with dementia, measures to ensure that they can remain in their own homes and receive individual support in order to ensure their safety and well-being might be considered disproportionate.

One might ask whether this is based on differences in the perceived value of the two groups, particularly as people with dementia are at risk of stigmatisation based on dementia as well as that linked to mental illness and age (i.e. ageism). There is a risk that promoting the right of people with dementia not to be moved against their will into institutions or nursing homes would put a burden on families to provide support which they may be unable or unwilling to give. Enabling people with dementia to remain in their homes might be favoured on economic grounds as long-term residential care (e.g. in an institution or nursing home) is more costly to the State than is home care. However, this is not necessarily the only solution and even if this solution was chosen by families and people with dementia, the necessary investment and organisation would be needed to ensure that families were able to cope and that the quality of life of people with dementia would not be threatened. Such support is often lacking and many people with dementia live alone. Some may have no surviving relatives or have no contact with them. This means that numerous people with dementia are being denied the opportunity to enjoy the same right to freedom as others because society is not organised in a way which responds to their needs.

Even where true choice is possible between being cared for at home or going into residential care, neither possibility may be ideal for some people with dementia (or their families). Other possibilities need to be considered such as assistive technology and live-in paid carers. In the case of the people with dementia who pose a threat to themselves or others, this would mainly involve supervision but would in addition provide social interaction and enable them to maintain their place within the community. Alternative

living arrangements might also be considered such as the “Wohngemeinschaft” in Germany which involves independent group living but with services brought into the group home if and when required. Another solution might be small homes of four to five people with dementia and one live-in professional carer albeit it in a family atmosphere. This approach is used, for example, in the Netherlands and in Belgium. In some cases, the homes are dispersed, in others there is row of such houses which makes the provision of additional services easier to organise. Possible solutions to avoid involuntary detention must be suited to the individual needs people with dementia, help reduce the risk of harm to themselves and others, and be proportionate to the perceived risk.

The necessity to consider possible alternatives before resorting to involuntary detention is enshrined in some laws and regulations covering involuntary detention. Sometimes, the possibility to provide the necessary protection within the person’s home is limited by their refusal (or that of their carer) to let health and social welfare providers in. It is also possible that the latter are hesitant to intervene in difficult situations involving decisions about autonomy versus neglect. The risk to the person with dementia in such cases could include malnutrition, self-neglect, dehydration, over-medication or under-medication and even abuse. The risk would be further complicated by insufficient knowledge as to the level of risk which may in addition increase over time. Decisions to restrict a person’s freedom may in some cases be influenced by fear of litigation.

Self-esteem and dignity

The issue of dignity is also involved and is linked to beneficence. The process of being involuntarily detained due to having dementia and representing a possible danger may be likened to other forms of detention such as that of people with other mental disorders and people who have committed crimes. In some countries, older people may also have memories of workhouses for the poor and houses of correction for homeless or disorderly people in which conditions were intentionally extremely harsh. People from these groups are or were typically stigmatised. Consequently, people who make this comparison may experience a feeling of injustice, self-stigmatisation, shame and loss of dignity. As will be discussed in section 2.3, institutionalisation involves more than a loss of freedom to choose where one resides. It is also a way of life which can be dehumanising and fail to respect people’s dignity. If people who have been involuntarily detained are not treated humanely and with dignity, respecting as far as possible their right to self-determination, it cannot be said that the measure respects the principle of beneficence or promotes their well-being.

2.1.2 Placement in long-term care or day care on a voluntary basis

People with mental disorders are sometimes detained on a long-term or daily basis due to their failure to protest or leave the building. If a person has not been legally detained, the various measures of protection offered by various laws and conventions which guarantee the right to liberty and security of the person (such as article 5 of the ECHR) do not apply. A person who has not been detained may therefore have less protection than a person who has. According to Gostin (2000), “Detention is a matter of “degree or intensity” (not “nature or substance”), with more severe restrictions rising to the level of “detention”.

Lack of real choice

In some countries, people are offered the possibility to be a voluntary resident/patient and be admitted on an informal basis. If they decline that offer, measures are taken to obtain legal authorisation to retain them on an involuntary basis. People may be inclined to accept voluntary status, perhaps due to the stigma attached to being involuntarily admitted to an institution on the grounds of mental disorder or perhaps due to the perception that “voluntary” implies some form of personal control over the situation. Similarly, a person might be persuaded to go to a day care centre as failure to do so would result in them being put in a care home. However, accepting the deprivation of one’s freedom in this way does not constitute a real choice. It is almost like asking somebody whether they would like to deprive themselves of their liberty or have someone else deprive them of it. It is not a question of whether but how freedom is going to be restricted. The absence of real choice constitutes a form of coercion.

Failure to protest

People may fail to protest against measures to deprive them of their liberty because they do not realise that they are free to resist or to leave. This might be the case if the process seems to be official, perhaps involving the police or the signing of documents. People with dementia who experience difficulties with language, memory and orientation may be at extra risk of confusion in this respect. There may even be deliberate attempts to create a misunderstanding. An example is the situation where a person with dementia is taken into a nursing home or respite care on an agreed temporary basis. They gradually become a long-term resident with requests to go home being ignored or skilfully managed up to the point that they give up, forget or “settle in”. In this way, people can be detained in fact but not in law. In some cases, it is possible that the person who fails to protest against entry into a long-term care establishment lacks the necessary capacity to make that decision. In that case, the relevant legal procedures should be initiated. In some countries, this may involve the appointment of a guardian with the right to make that decision. In others, it may involve a legal procedure to decide on involuntary detention. The deprivation of a person’s liberty based solely on passive acceptance of such a restriction cannot be considered as ethically or legally justified.

Following an appeal to the European Court of Human Rights regarding what has come to be known as the *Bournewood* case (*R v. Bournewood Community and Mental Health NHS Trust*), it was decided that a man had been detained unlawfully in the meaning of article 5 of the European Convention on Human Rights. The man in question, who had severe autism and a learning disability, had spent much of his life in hospital. Having left hospital and following an episode of agitation whilst at a day centre, he was readmitted as an emergency to the psychiatric hospital where he had previously lived. This was an informal admission based on his passive acceptance of the restriction of his freedom. However, his carers and a cousin challenged his detention. The High Court determined that he had not been unlawfully detained, the Court of Appeal that he had, the House of Lords that he had not and finally, the European Court of Human Rights that he had (for a period of approximately three months). One of the judges in the House of Lords, despite concluding that unlawful detention had not occurred, stated that the argument that the

man had been free to leave was “stretch(ing) credulity to breaking point” (Scottish Law Commission, 2012, p.7). Similar cases of unlawful detention are probable in the case of people with dementia.

Restriction of freedom despite protest

As involuntary detention is judged on the basis of degree or intent rather than the nature of the restriction of freedom, some forms of involuntary restriction of freedom seem to be relatively ignored. Attendance at day care centres is normally on a voluntary basis but some people with dementia are cajoled or more forcibly put into mini-buses and taken there against their will. Once there, the doors are locked or they are prevented, by various means, of leaving before the set time when they are taken home or picked up by relatives. In some cases, they are free to leave, but as the bus does not return until the end of the day, they would have to make their own arrangements to return home and may not have the means or ability to do so. Many struggle in vain against such restrictions and suffer frustration and emotional distress. This may lead to obstructive behaviour which may in turn be managed by further restrictions of their liberty.

Whilst they may represent a threat to themselves if left alone during the day, the grounds for involuntary detention are either not met or involuntary detention is not considered to be in their best interests. Moreover, the option of day care may be the least restrictive measure, proportionate to their perceived needs and considered as the best option in terms of their well-being. Nevertheless, they have not consented to attend day care and cannot be lawfully obliged to attend or to remain there once at the day care centre. This situation is unsatisfactory as people are being unlawfully deprived of their freedom due the lack of legal process or informed consent. It would be impractical to require a legal procedure to take a person to a day care centre especially as attendance may be irregular. Also, whilst a legal process may ensure the lawfulness of a person’s presence, it is no guarantee of good care. It is therefore important to take all possible measures to enable a person with dementia to express consent or refusal and this might be best achieved by means of supported decision making (described in section 1.3.2).

The whole issue of consent is undermined in the case of non-disclosure of the diagnosis. A person cannot give fully informed consent to dementia-related issues if they do not know that they have dementia. The diagnosis is crucial information when weighing up the pros and cons of issues such as attendance at a day care centre. A proper process to determine the legal justification for the admission of people with dementia to day care centres should be put in place. This would not necessarily reduce the anguish experienced by some people with dementia at being forced to go to a centre. However, it would be more ethical and help assure better levels of protection and respect of their right to freedom.

2.1.3 Advocacy

People with dementia are not always aware of restrictions of liberty or that they have any choice or can challenge decisions. Some may be aware of their rights but not know what to do if they are not respected, feel that no one would take their concerns seriously or not

know whom to approach. There may also be power issues involved in that the person to whom complaints can be made may be responsible for the failure to respect the person's rights or may appear to be in tacit agreement with certain unfair or discriminatory practices. There is therefore a need for independent advocacy (i.e. for someone to speak on behalf of the person with dementia when necessary in order to protect their rights and interests). Anybody could, in theory, report an injustice or speak on behalf of a person with dementia who has concerns about an injustice or about a person with dementia whom they feel is being treated unjustly. However, it is important that advocates are recognised as having the authority to act on someone else's behalf and are able to take the necessary action. Also, not everybody has a trusted person in whom they can confide. For the sake of justice, every person whose freedom is restricted in any way should have access to an independent advocate.

2.1.4 Recommendations on freedom to choose one's residence or place of stay

In accordance with the principle of subsidiarity and discrimination, services and support should be developed which provide an alternative response than that of involuntary detention to situations whereby people with dementia lack capacity and represent a danger to themselves.

Such services and support, including a range of alternative living arrangements, should be adapted to the needs of people with dementia, taking into account individual preferences. Legislation and guidelines on the deprivation of freedom should include a clear definition of that term.

No person with dementia should be detained "in fact but not in law" and thus deprived of the legal safeguards attached to involuntary detention.

There should be greater monitoring of how legislation to involuntarily detain people with dementia is used.

The conditions for the involuntary detention of a person with dementia should include proof that they not only have dementia but are considered to be in danger or at risk if not so detained.

Steps should be taken to ensure that legislation on involuntary detention does not exclude people with dementia (e.g. by being limited to psychiatric institutions or to the possibility of curative treatment).

Education and safeguards are necessary to prevent the practice of relatives "giving consent" to admission on behalf of someone who cannot or does not consent.

Health and social care professionals should be provided with guidelines and training on how to assess capacity and potential risk in relation to specific situations.

People with dementia should have the right to appeal to the court against the decision to involuntarily detain them, against the choice of the establishment and against the way they are treated once detained. To make this right meaningful they will need access to independent advocacy.

A system of advocacy should be developed for people with dementia who are being detained involuntarily or whose freedom is being restricted in any way.

The system of advocacy for people with dementia should contain measures to ensure that advocates are independent, effective and recognised.

Judges and lawyers should be better informed about the social and psychological aspects of dementia and about the nature of capacity and incapacity in relation to dementia.

Representatives of people with dementia in court cases involving a possible restriction of freedom should be attentive to stereotyping of people with dementia which might affect assessment of the necessity for involuntary detention.

Regular and timely assessments of care needs and potential threats to the safety of people with dementia should be carried out and appropriate support provided if necessary as a means to avoid involuntary detention resulting from a crisis situation.

The lawfulness of restrictions of liberty occurring in residential respite care, day care facilities and other places where people with dementia reside voluntarily should be investigated with a view to the development of guidelines and an accessible system of safeguards.

Legislation should cover the deprivation of freedom of people with dementia at home (e.g. not being permitted to leave the house or being locked in a room).

Procedural safeguards should be developed to protect the rights and well-being of people with dementia in residential respite care and day care, and in other places where they are not free to leave but have not been lawfully detained.

Clearer and fair consent procedures should be developed to cover decisions which might result in a restriction of the liberty of people with dementia.

The practice of supported decision making should be promoted in all discussions with the person with dementia about possible restrictions of freedom.

It should be obligatory to document any restriction of freedom, to inform the person with dementia (or their legal representative) of any restriction of freedom and to inform the latter of their legal rights in relation to that restriction as well as of the contact details of any advocacy or legal aid to which they are entitled.

Appropriate resources, practices and infrastructure should be provided to enable people with dementia to be cared for in their own home for as long as reasonably possible and desired by the person with dementia.

Care should be taken when devising protective measures and standards of care to avoid inadvertently creating situations which actually result in a loss of freedom of people with dementia as they are unattainable.

Policymakers should ensure that the decisions they take are shaped and influenced by the social context in which people live.

2.2 Freedom to live in least restrictive environment

In section 2.1, we considered whether it is ethical to deprive people of their freedom on a permanent or temporary basis in a particular place. In this section, we look at different measures used to keep people in a particular place (irrespective of whether they are voluntarily or involuntarily in that place) as well as measures to prevent movement or choice of action, or to make people comply with another person's wishes.

Such measures will be referred to collectively as measures of restraint. The use of coercion is slightly different to other forms of restraint as the emphasis is on forcing a person to do something rather than preventing them from doing something. However, as explained in section 1.1.4 (definitions), it amounts to a restriction of freedom. Other forms of restraint although often conceptualised in terms of a restriction also result in forcing a person to remain in a certain place, to be immobile or to do something other than that which they wanted to do. Whilst recognising that there is a subtle difference between the two terms, coercive measures will be included in the term "measures of restraint".

In the following sections, different measures of restraint are briefly described and the ethical implications of their use considered. This will be followed by a more global consideration of the ethical issues related to the use of restraint in general and in particular in residential care settings.

2.2.1 Physical restraint

Description and examples of physical restraint:

The American Food and Drugs Administration (FDA) defines "protective restraint" (in 21 CFR Section 880.6760) as:

"a device, including but not limited to a wristlet, anklet, vest, mitt, straight jacket, body/limb holder, or other type of strap that is intended for medical purposes and that limits the patient's movements to the extent necessary for treatment, examination, or protection of the patient or others"

This is clearly set in the healthcare context, is heavily influenced by notions of intent and purpose, and focuses on measures which actually touch the person's body. The American

Health Care Financing Administration (HCFA) (in 42 CFR Section 483.13 (a)) defines physical restraint under the Interpretive Guidance in the State Operations Manual as:

“any manual method or physical or mechanical device, material, or equipment attached or adjacent to the individual’s body that the individual cannot remove easily which restricts freedom of movement or normal access to one’s body.”

The HCFA definition is functional and focuses on the effect on the individual. It is not limited to devices which touch the body but includes those which are adjacent to the person. This would include anything from a strait-jacket, to a tray table or to a side rail. It would even include a sheet if that had the effect of restricting the person’s freedom of movement (Westmoreland and Feigal, 2000). Variations of the HCFA can be found in several European studies and whilst it was devised to be applicable in nursing homes, it could also be applied in a range of settings, including the hospital and in people’s homes. It does, however, combine measures which are applied directly to the body and devices which are adjacent to a person, which are qualitatively quite different and it does not include any reference to the degree of restriction imposed by the measure. As mentioned in section 1.3.4, with regard to the difference between restriction of freedom and deprivation of freedom, the degree or extent of the restriction is important.

Examples of direct physical restraint (i.e. touching the body) would include various types of straps and belts, strait-jackets, limb holders or mittens and in certain circumstances, various medical devices such as tubes and drips. Physical restraint, involving less direct contact with the body in the sense of not binding it to something or to itself, would include bed rails, bed nets or cages, trays fixed to chairs, wheelchair brakes and bars (Gallinagh et al., 2001; MDAC, 2003; Retsas, 1998). Furniture may also serve as means of restraint if it restricts or prevents mobility such as chair which tilts backwards (Retsas, 1998). This emphasises that the way that objects are used and the effects of this are important in determining whether it is a form of restraint. For example, a sheet is not a form of restraint *per se* but it is when it is tucked in so tightly that a person cannot move, irrespective of whether this was the intention. The same applies to chairs which tilt backwards. There may be no intention to restrain and people may use them willingly, especially if they are the only chairs available to sit on, but they may result in a restriction of freedom of movement.

A cage bed is a cage fitted on top of a bed which serves to confine a person to the bed (MDAC, 2003). The cage may be made out of metal bars or a net but the end result is the same. Examples of the use of this form of restraint in psychiatric hospitals and residential social care homes have been documented (MDAC, 2003). It is slightly different to other forms of restraint in that it is neither attached to the body nor adjacent to it. The person is inside the bed and cannot get out. It is nevertheless a device which restricts people’s freedom.

A person’s freedom to move about or even to move parts of their body may be restricted by a medical device such as a drip or tubes attached to a machine. If the person believes that this is essential or fears the consequences of disconnecting it, it may serve to restrict

their freedom of movement. Depriving a person of necessary medical aids such as a walking stick, a Zimmer (walking) frame, a wheelchair or a mobile drip to which they normally have access may also prevent a person from moving about freely and could therefore be considered as a means of restraint as illustrated in the following quote.

"A resident in a wheelchair had been moving around the corridor during the night and staff had assisted him back to bed. The staff had removed the wheelchair from the room." (Commission for Social Care Inspection, 2007, p.38).

The above example suggests a situation involving the intent to restrict freedom of movement. However, it would still consist of restraint, were such intent lacking.

The issue with regard to medical devices is somewhat different and less clear cut in that people's freedom of movement may be restricted solely for the purposes of treatment, which is in many cases standard practice (e.g. the intravenous administration of hydration, antibiotics or blood, and the drainage of bodily fluids). Yet such measures may restrict a person's freedom of movement. Presumably consenting to the procedure after having been fully informed of what is involved might determine whether the procedure is treatment or restraint. This raises further issues as to whether restraint consists solely of restrictive measures to which a person has not consented and also to whether the intent is to restrain. So far, we have argued that the main criteria are that something restricts freedom of movement and this irrespective of questions related to consent and intent. However, it would be unrealistic to consider the provision of hydration to a person who needs it as a form of restraint. Perhaps with regard to medical devices, issues such as intent, purpose and necessity are in fact relevant to the debate about whether they represent a form of restraint.

The prevalence of the use of physical restraint

Reviews of the literature on the use of physical restraint in residential and semi-residential care facilities suggest that it is widespread (Goethals, Dierckx de Casterlé and Gastmans, 2012; Hantikainen, 1998). However, it is difficult to obtain a reliable indication of its use and the prevalence of the use of physical restraint on people with dementia tends to be lost amongst general statistics on its use on nursing home residents. Figures for the prevalence of the use of physical restraint on people with dementia in their own homes are lacking.

Reports in the literature of its frequent use on older residents in nursing homes vary between 25% and 85% (Hantikainen, 1998). In Norway, the use of restraint in care homes is reportedly quite common with an average of 77% of residents in care homes having dementia and 69% having experienced the use of restraint (Engedal et al., 2000 in Slettebø and Haugen Bunch, 2004). Hammers and Huizing (2005), on the other hand, estimate the prevalence of physical restraint in care homes as being between 41% and 66%. In Spain, the Spanish Untie the Elderly Programme maintains a database on the use of restraint in a representative sample (check) of 667 facilities covering 27,332 residents of care homes. The data, which was obtained by means of a survey completed by the various facilities, reveals that in 2011 23.67% used physical restraint (based on the HCFA

definition of physical restraint mentioned above. However, the prevalence of the daily use of physical restraint solely for people with dementia amounts to 63%.

Gastmans and Milisen (2006) suggest that different estimates of prevalence may be due to differences in the categories of people studied, as well as cultural, legal and educational differences and the research methods used (e.g. observation, self-report or medical files). In countries where there are strict regulations on the use of physical restraint, depending on the methods used, it may be difficult to detect all cases of its use. Survey methods and interviewing may result in the desire to provide a more socially acceptable image of the institution or staff. On the other hand, direct observation runs the risk of organisations and staff being careful not to reveal the use of restraint whilst the observer is present. There is no ideal solution and the studies provide valuable information about the use of restraint against older people and/or people with dementia, bearing in mind that the actual use of restraint is likely to be somewhat higher.

The existence of guidelines or regulations on the use of restraint, provided that they are known about and sufficiently understood, may result in a less use of physical restraint in professional care settings (Karlsson et al., 2000; Weiner et al., 2003).

Reasons for and attitudes towards the use of physical restraint

A number of reasons for the use of physical restraint have been identified in studies. Some are linked to the person to whom the measure is applied, such as to prevent them from harming themselves, to prevent falls, due to suicidal tendencies and restlessness. However, the prevention of harm is clearly not the only reason and the use of restraint has been proven to cause harm. Some reasons are based on a disturbance to other people such as aggressive behaviour, sexual harassment of staff, disturbing other residents or going into other people's rooms. The occurrence of BPSD (see section 1.3.1) or any behaviour which carers find challenging may sometimes result in the use of restraint if the carers are not sufficiently trained, unaware that the use of restraint may result in harm or do not have access to the support they need. The following table provides examples of challenging behaviours which are classified as either aggressive or non-aggressive.

Aggressive and non-aggressive challenging behaviour (CB) (Ian James, 2012)

Aggressive forms of CB	Non-aggressive forms of CB
Hitting	Repetitive noise
Kicking	Repetitive questions
Grabbing	Making strange noises
Pushing	Constant requests for help
Nipping	Eating/drinking excessively
Scratching	Over-activity
Biting	Pacing
Spitting	General agitation
Choking	Following others/trailing

Hair pulling	Inappropriate exposure of parts of body
Tripping	Masturbating in public areas
Throwing objects	Urinating in inappropriate places
Stick Prodding	Smearing
Stabbing	Handling things inappropriately
Swearing	Dismantling objects
Screaming	Hoarding things
Shouting	Hiding items
Physical sexual assault	Falling intentionally
Verbal sexual advances	Eating inappropriate substances
Acts of self-harm	Non-compliance

Sometimes restraint is used because it has been requested by the person with dementia, by relatives or by a doctor. If prescribed by a doctor, nursing or care staff may feel obliged to carry it out and fear reprisals for acting against a doctor's wishes (Karlsson et al., 2000). The decision to use restraint is not always made by one person. In some cases, it is made by the care or medical team.

Some reasons reflect a perceived benefit to other people (e.g. when it is due to understaffing, lack of competent staff, the desire for peace and quiet, lack of knowledge about alternatives to restraint and about the consequences of using restraint) (Gastmans and Milisen, 2005; Hantikainen, 1998; Kirkevold and Engedal, 2004). The routine use of physical restraint (especially bed rails) or for reasons which are unclear has also been reported (Cohen-Mansfield et al., 1992 in Hantikainen, 1998; Kirkevold and Engedal, 2004; Meyer et al., 2008). As physical restraint is often used arbitrarily, it is not always documented. Kirkevold and Engedal (2004) suggest that lack of legislation of the use of physical restraint may explain why it is not always reported or reasons given for its use.

The perceived need to protect people from harming themselves, particularly due to falls, is a common reason given for the use of restraint (Hamers and Huizing, 2005; Karlsson et al., 2000) and is often linked to fears of litigation. However, it has been argued that such fears are often unfounded and result from a lack of knowledge about liability for negligence and physical injury (Robbins, 1996). Moreover, physical restraint may actually increase the likelihood of falls and cause severe injury. In addition, it could be argued that too great an emphasis is placed on the prevention of harm at the risk of overlooking the need to promote autonomy and general well-being.

A lack of legislation banning the use of physical restraint may allow it to persist. In Japan, for example, it is forbidden to restrain older people receiving long-term care but people with dementia in hospital are not accorded the same protection. Consequently, it is fairly common for hospital nurses to physically restrain patients with dementia in order to prevent them from removing intravenous infusion tubes (Yamamoto and Aso, 2009). A difference between the use of restraint in psychogeriatric wards of nursing homes and hospitals in Israel was also reported in a study by Weiner, Tabak and Bergman (2003) but

this was explained in terms of the nurses in nursing homes having greater knowledge about guidelines on the use of restraint.

Just as carers may have reasons for using physical restraint, they also have reasons for removing it once applied. In a small Swedish mixed methods study, 30 registered nurses were given a semi-structured interview based on a vignette about a fall-prone person with dementia but with limited information about the situation (Karlsson et al., 2000). Part of the study involved asking the nurses whether they would respect the person's wishes and remove the physical restraint which had been applied. Only 9 stated that they would and of the remaining 21, 8 initially said that they would but then changed their minds. Of those who would remove the restraint, reasons given were to prevent harm (through agitation or the person feeling poorly), to respect the person's autonomy and on a conscious decision to take the risk themselves that the person may fall and injure himself. The researchers point out that the reasons not to continue the use of restraint were related to ethical values whereas those to continue restraint were mainly related to external factors such as lack of time. Nevertheless, all of the nurses opposed to removing the restraint would do so for at least one of the reasons provided in addition to the additional vignette (e.g. based on restraint being forbidden, the staff-ratio being high or removal having been requested by a doctor or the family or knowledge that the person previously said he could not imagine being restrained). Whilst the initial nine nurses were prepared to take risk, the other nurses' decisions to remove restraint were largely dependent on the decisions of other people.

These results cannot be generalised to all nurses but they provide valuable information about the reasoning of a group of nurses with regard to the use of restraint which may be applicable in similar situations with regard to similar groups. Reflecting on the findings, the researchers suggest the importance of different attitudes towards the person who is restrained and personal responsibility. In particular, they interpret the reasons of the 9 nurses who were willing to remove the restraint as reflecting an understanding of the person's behaviour being meaningful as opposed to a symptom of the disease, as well as to them being willing to take independent decisions.

The impact of physical restraint

Numerous examples of the negative impact of physical restraint can be found in the literature. These include medical/physical, mental/psychological, social/behavioural consequences and mobility/agility. Examples are provided below. This is an artificial distinction as many consequences are linked to more than one area.

Medical/physical consequences include bruising, acute functional decline, decreased peripheral circulation, cardiovascular stress, bladder and bowel incontinence, constipation, muscle atrophy, pressure ulcers, infections, asphyxiation, strangulation, cardiac arrest and even death (Cotter, 2005; Cotter and Evans, undated; Evans et al., 2002; Gastmans and Milisen, 2005; Parker, 1997). Such effects are not linked solely to the use of physical restraint as older people with cognitive and physical impairments may be more prone to such harmful effects compared to those with no impairments (Gastmans and

Milisen, 2005). Evans et al. (2003) suggest that as estimations of the number of actual deaths linked to the use of restraint are mainly based on retrospective studies (e.g. consulting death certificates), it is likely actual cases may be much higher.

Mental/psychological consequences include serious psychological disadvantages, psychological trauma due to restraint serving as a symbolic reminder of past victimization, increased cognitive decline, apathy, depression, disillusionment (Evans et al., 2002; Flannery, 2003; Gastmans and Milisen, 2006).

Social and behavioural consequences include impaired social function and behavioural symptoms such as aggressiveness and regressive behaviour (Cotter, 2005; Evans, Wood and Lambert, 2003; Hamers and Huizing, 2005).

Consequences linked to mobility and agility include decreased muscle strength and balance, decreased mobility, increased risk of falls and injury, even resulting in death (Capuzeti et al., 2000 and 2002; Evans et al., 2002; Tinetti, Liu and Ginter, 1992).

With regard to mobility, Luo, Lin and Castle (2011) found that the use of trunk restraint was associated with a higher rate of falls and fractures amongst people with dementia compared to people without dementia. The use of full bed rails was associated with a lower risk of falls for people with and without dementia. This study was based on a survey covering a random sample of 13,507 residents in nursing homes. Staff members provided the responses based on medical records and other documentation. Residents were not interviewed. It was found that people with dementia were more likely to be restrained and slightly less likely to have bed rails. Cotter (2005) describes the risk of people who have been physically restrained becoming trapped between the headrest, mattress and bedrail which can lead to asphyxiation and strangulation. People may fall as a result of struggling over barriers (such as bedrails) or as a result of fatigue or unsteadiness following an effort to free themselves from a restrictive measure (Cotter, 2005).

The impact of physical restraint is not limited to those who are subjected to it. Gastmans and Milisen (2006) point out that there has been very little research into relatives' experience of the use of restraint on their loved ones. They suggest that relatives may be affected in various ways. Some, for example, consider the use of physical restraint as a sign that all hope is gone, some prefer to ignore that it is being used and yet others experience anger or disillusionment. The use of restraint may also reflect and even contribute towards unequal power relations.

Ethical issues linked to the use of physical restraint

Respect for dignity

Treating people with dementia with dignity should perhaps be considered as one of the most important ethical principles to be observed when providing care and specifically with regard to the issue of the use of physical restraint. Human dignity (in the sense of "Menschenwürde") is often considered as inherent in being a human being and some-

thing that cannot be taken away from a person (Nordenfelt, 2002). However, this is just one interpretation of what dignity means.

There is also the dignity of identity which is 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. A person's perceived value and worthiness is reflected back in the context of interaction. Dignity can therefore also be considered as an attribute that can be subjectively felt but also something which can be denied, ignored, withheld and violated. It is often linked to a person's self-image, which has evolved and been fostered over many years but which can be damaged by the acts of other people. This type of dignity can be shattered by other people, even unintentionally due to a failure to really understand each person i.e. who or what kind of a person they really are. The dignity of identity provides a possible explanation for the humiliation suffered as a result of being visibly or publicly restrained. Such humiliation may also result from cultural expectations linked to adulthood and associations with measures sometimes used to restrain children (e.g. putting rails around cots, putting them in play pens, tucking them tightly in bed, making them wear mittens and using harnesses, reins and wrist links to stop them wandering off).

Nordenfelt (2002) explains that the dignity of identity can also be considered objective because it can be violated even in cases where a person is not aware of the violation. Consequently, it would be a violation of a person's dignity if they were physically restrained in a way which another person would find undignified even if the person restrained is unconcerned or even unaware of the measure. This would also be applicable in the case of chemical restraint which might have an impact on a person's appearance and visible behaviour.

Personhood - The degree of restraint and objectification

As mentioned earlier, the distinction between the restriction or deprivation of freedom is based on a consideration of degree or intensity of a particular measure. Restraint of various degrees or levels of intensity may be used as the actual means to deprive a person of their freedom or to restrict it. However, rigorous legislation, recommendations or guidelines are sometimes lacking on the use of physical restraint. As most forms of restraint do not constitute a deprivation of freedom (as loosely defined, for example, in the ECHR), there is a risk that they may be tolerated. However, the degree or level of intensity is not entirely an objective measure.

What one person may consider as a slight restriction of their freedom or as being of minimum importance, may be devastating for another person based on the meanings attributed to the measure and the significance of being restrained in that way for that person. This may be based on the person's history, experience, values and expectations, as well as on the importance placed on the impact of the restriction. For example, one person might not object in the slightest to being tucked in bed so tightly that they cannot move. That person may interpret that as a caring act, not be someone who moves much during the night or not even pay much attention to it. Another person may feel that it is an

extreme form of restraint which even intrudes into their periods of sleep, liken it to the swaddling of an infant and consider it humiliating, malicious or an abuse of power. Failing to take into account each individual's reaction to the measure amounts to treating the person as an object to which restraint is applied and not as a unique individual. Such practices fail to respect personhood.

As stated earlier, the intent to restrict liberty does not affect whether a particular measure constitutes restraint and also, the fact that a person does not oppose the use of a particular measure does not necessarily make it acceptable. On the other hand, understanding the way that a measure is experienced by the person on whom it is applied is part of providing good care and judging levels of restraint. Attention to such details may contribute to uncovering practices and methods which physically restrain people but which are not recognised as such.

Justice and equity – Discrimination, devaluation and power

Various forms of restraint have been practiced throughout the ages. Examples include putting people in small cages, fastening them to walls, the use of shackles and chains and putting people in public stocks. Such practices were inflicted on people who were considered as having no rights, no value or having committed a crime. The intention was to cause physical and mental pain or anguish, and/or to humiliate people. Other practices such as swaddling infants may have been linked to beliefs about care and the formation of the body and have not completely died out. Although restraint was often deliberately designed to cause pain in the past and this is presumably not the intention with current means of restraint, people may consciously or unconsciously associate measures to restrict their movement with such well known means of punishment.

According to the principle of justice and equity, people should be treated on the same basis and not be disproportionately subjected to risk, harm or even preferential treatment. However, restraint seems to be used against certain groups of people and not others. It is often used against people who do not have the right or ability to oppose it such as people who have been compulsorily detained, and potentially vulnerable groups such as infants, older people and people with physical or mental impairments. Whether this is because such groups are easy targets and cannot fight back (which would consist of an abuse of power) or whether it is because they are not valued, is not known. However, the groups which are subjected to such practices are groups in society which are often less valued than other groups and such practices are therefore tolerated. In a paper by Minkowitz (2006), then Co-Chair of the World Network of Users and Survivors of Psychiatry, she describes discrimination as occurring “first of all, by making an exception of actions against people with psychosocial disabilities, actions which would otherwise be considered torture” (p.15).

The use of restraint, if not challenged, could be considered as representing a form of structural discrimination, based on the devaluation of people with dementia and on the unfair exercise of power which would also be against the principles of justice and equity. Structural discrimination is the kind of discrimination which is inherent in societal

practices and traditions and often unrelated to a personal wish to treat another person or group unfairly. Sometimes such discrimination is so deeply engrained in society and daily life that people may be surprised at the suggestion that there is anything wrong with what they are doing. They may argue that there is no malicious intent and that it is just the way or even the only way that things are done.

Link and Phelan describe power as one of the components of stigma, the others being labelling, stereotyping, separating “us” from “them” devaluation, discrimination and emotional reactions. Power can be detected behind every component of stigma and without the social, political and/or economic power of the people who stigmatise, there would be no stigmatisation (Link and Phelan, 2006; Mahajan et al., 2008; Parker and Aggleton, 2003). People with dementia tend to be older, be considered as having a mental disorder and the majority of older people with dementia are women. This adds to the stigma of dementia that linked to mental illness, as well as ageism and sexism. Some people with dementia may be further stigmatised on the basis of other attributes linked to ethnic groups, religious beliefs, sexual orientation or lifestyle factors. In addition, some people with dementia will have lost certain rights and no longer be considered competent to make certain decisions about their lives. These attributes, which become socially salient due to the significance that they have for other people, often reflect power imbalances within society which are reflected in attitudes, presumed social status and socio-economic differences. Admittedly, many care homes have a high turnover of staff, who are predominantly female and from all groups in society, some of which are also traditionally devalued. However, it is the combination of various potentially discrediting attributes which render people with dementia vulnerable to abuse in the form of physical restraint.

Beneficence – For whose benefit?

The concept of structural discrimination does not exonerate individuals from blame because each person can take a stance against injustice. Often there are several issues at stake. Professional carers have a professional duty to care and this involves accomplishing a range of tasks within a given time. Failure to accomplish tasks on time may be problematic for them and be interpreted as a sign of laziness or incompetence. Certain practices, such as the use of restraint, may be overtly or covertly condoned or even promoted by a care home, thereby making it difficult for staff not to use them as it would mean going against the hierarchy. Some homes may simply turn a blind eye to various practices in the interests of efficiency and cost saving.

Informal carers may feel that they have a moral duty to care or simply care based on a loving relationship with the person with dementia. Some point out that they had no option, did not choose to be a carer or just drifted into care (Alzheimer Europe, 2001). Non-related informal carers, such as neighbours and volunteers, which are less common, may care for a variety of reasons (e.g. based on religion, community spirit, reciprocity or friendship). Family carers may also experience conflicting demands which lead to the use of physical restraint. This might include professional obligations, competing family demands, the need to leave the home (e.g. for shopping or for administrative matters) and personal reasons (e.g. based on leisure activities, socialising or having a break).

The reasons provided above are examples of real-life situations which sometimes contribute towards the use of physical restraint and not justifications for its use. They highlight the dilemma sometimes faced by professional and informal carers which consists of balancing competing demands, wishes and obligations. Caring for a person with dementia should involve doing what is in their best interests, which rarely if ever involves the use of restraint. Yet, as mentioned earlier, people with dementia often lack the power to protest, may be easily manipulated and, being dependent on the carer, are in a vulnerable position. The onus is therefore on carers to respect the person with dementia and to act in their best interests. This is an ethical perspective which does not resolve the conflict mentioned above.

A perceived problematic situation cannot be considered as a justification *per se* for the use of physical restraint. Equally, the problematic situation is not caused uniquely by the person with dementia. It may also be a reflection of the way that the care of people with dementia is organised by society which reflects economic, political and social factors, which in turn may be a reflection of the value accorded to people with dementia. Defining a person's behaviour as problematic or challenging begs the question "for whom?" All too often the answer is not "for the person with dementia" but rather "for other people". Physical restraint would rarely be in the best interests of the person with dementia and unless it is, it should be considered unethical.

Nonmaleficence

Nonmaleficence, which means doing no harm, is particularly relevant to the issue of physical restraint. As seen in the section on the effects of physical restraint, physical restraint can have serious adverse physical, psychological, emotional and social effects, and even lead to death. Based on the principle of nonmaleficence, its use cannot in general be considered as ethical although it is always possible that there may be exceptional circumstances. On the other hand, there is a risk that the initial use of restraint may exceptionally be justified but that its use is continued thereafter, when there are no longer grounds to justify its use. This may also apply to the use of certain medication.

Respect for autonomy

The issue of autonomy with regard to the use of restraint applies first and foremost to the people with dementia whose freedom is restricted in that way. They are being deprived of the freedom to decide what they want to do and when, or what they would prefer not to do. However, this is not simply about having the freedom to choose one option over another. The consequences of the lack of freedom of choice are inextricably linked to other losses of freedom such as the freedom to physically move, to respond to one's physical needs, to present a certain image of oneself, to protect oneself against humiliation and possible abuse, to socialise with other people and to accept risks. Respect for autonomy is not more important than other ethical principles but in the case of restraint, it lies at the heart of several ethical issues and the eradication of the use of restraint would help avoid certain unethical situations in the context of care.

The autonomy of care staff is not being respected if they are expected to use certain forms of restraint in order to fulfil their required tasks and if they are uncomfortable with this either professionally or personally. One way to express their autonomy is to voice their concerns or cease working for that establishment. However, if such use is widespread and accepted by apparently respectable establishments and more highly educated healthcare professionals, it is possible that they may question the legitimacy of their concerns. For this reason, it would be beneficial to include training in ethical reflection in the formal training of care staff and as in-house or external continuing education. Training in ethical issues related to the care of people with dementia would also be beneficial for managers of care homes as it might lead to a more positive attitude towards care staff who express ethical concerns.

Security versus well-being

The use of restraint is often justified on the grounds that it is necessary to prevent a person from coming to harm. We have already argued that far from preventing harm, the use of restraint may actually lead to accidents and even death. Arguments based solely on the principles of beneficence and nonmaleficence are therefore unconvincing. Another point to consider is whether and if so to what extent people with dementia should be protected from harm. As a potentially vulnerable group (and in the light of fears about litigation for failing to protect them), people with dementia may be over-protected. This reduces their autonomy, may fail to respect their dignity and overall, is not compatible with enhancing their quality of life. Often greater importance is attributed to safety than to well-being especially when it concerns other people who are considered as vulnerable and for whom someone is responsible. It may be considered acceptable for people to engage in acrobatics and mountaineering, even to surf in shark-infested water, as a hobby or to cross busy roads, handle hot liquids and manipulate machinery but not for an elderly lady with dementia to get up out of her chair when she chooses in order to walk around a little and chat with other residents. Gastmans and Milisen (2006) suggest that although physical integrity may be considered as a fundamental value, this value should not always take priority over others and that consequently, overall well-being should be promoted. This would include social, psychological and moral aspects of well-being.

Goethals et al. (2012) reviewed qualitative literature on nurses' decision-making in the case of physical restraint. Concerning the issue of security and well-being, they point out that nurses' decisions to use physical restraint are nevertheless often dominated by concerns about safety even though they take into consideration other values such as beneficence, freedom and respect for autonomy when deciding on the use of restraint. They also consider well-being in terms of the well-being of staff and other patients as well as that of the person in question. This is an issue which probably also applies in the context of people's own homes where there are other family members to consider. In a care environment which prioritises safety over well-being, nurses (and care staff) may be torn between their own values and their perceived or imposed professional responsibilities. Weiner et al. (2003) describe them as "acting as "double agents", trapped between

professional and ethical obligations towards patients' rights and the obligation to carry out employers' policies, which may involve cost-saving and efficiency measures" (p. 513).

Care may become a series of physical acts devoid of any genuine care for the person concerned. If nurses try to cope by rationalizing the use of physical restraint rather than prioritising total well-being, there is a risk of distancing which may make it easier for them to apply such restraint (Sullivan-Marx, 1996 in Goethals et al., 2012). This corresponds to the conceptualization of stigma of Link and Phelan (2001) in which making a separation in one's mind between "us" and "them" is associated with a perceived loss of status of "them" which makes it easier for the people considered as "us" to discriminate.

Addressing issues often linked to the use of restraint

Most of the literature is on the use of restraint in professional care settings, but most of the literature on addressing issues which commonly lead to the use of restraint also seem applicable to the home setting. Some of the issues discussed in the literature are reflected in the recommendations of this working group.

Modification of the environment and of procedures

In addition to the removal of bed rails and other forms of physical restraint, Cotter and Evans (undated) suggest the need to implement necessary changes to the environment and to procedures. They suggest, for example, the use of surveillance, implementing measures to ensure bed safety and to protect against falls and injuries, personalizing the environment with objects and photos, encouraging families to take part in care and striving for consistency of both staff and care routines. Part of changing routines might involve providing care.

Communication

The issue of communication has been addressed by several researchers. Some describe the need to speak clearly, slowly and calmly, using non-verbal communication if needed, whereas others emphasize conversation, negotiation, involving people in decisions about their care, giving them responsibility (Cotter and Evans, undated; Kontio et al., 2010; McKillop and Petrini, 2011; Slettebø and Haugen Bunch, 2004). These approaches all involve personal contact and involvement with the person. Such presence and interaction should be meaningful. Chiovitti (2011) mentions the importance of authentic relating which is reminiscent of the work of Buber (1970) as well as Kitwood (1997). Buber emphasized the importance of relating to people authentically (i.e. as people rather than as objects), whereas Kitwood described the downward spiral towards objectification, isolation, increased impairment and death.

Carers may experience difficulties communicating with people with dementia due to a lack of training or understanding of what dementia involves. It cannot therefore simply be suggested that they communicate more with the person with dementia in their care. Organisations have a responsibility to ensure that professional carers are adequately trained to maximise the possibility of effective communication and also to help them to establish a meaningful care relationship with people with dementia in their care. Numer-

ous publications and guides are available on effective and meaningful communication with people with dementia, and many Alzheimer Associations run training courses on this issue.

Part of communication involves the interpretation of the message or behaviour of the person with dementia, Chiovotti (2011) also emphasises the importance of not taking behaviour personally. Some messages and behaviour may be correctly interpreted and were intended to be obstructive or against the carer. Everyone has the right to express themselves, get frustrated and react to others as they see fit. This includes people with dementia. However, when people have difficulty communicating with and understanding people with dementia and when people with dementia are unable to communicate what they wish to communicate, misunderstandings will occur.

Educational programmes

The findings of a few studies suggest that educational programmes may be beneficial in helping change attitudes and encouraging restraint free practices. Pelfolk et al. (2010), for example, evaluated the effects of a restraint minimisation education programme on staff knowledge, attitudes and the use of physical restraint by means of a randomized controlled trial. The participants in this Swedish study included 184 staff in the group receiving the educational programme and 162 staff in the control group (which received six 30-minute videotaped lectures). The education programme ran for 6 months and covered six themes including dementia, delirium in older people, falls and fall prevention, the use of physical restraint, caring for people with dementia and complications in dementia. The emphasis was on understanding, preventive measures, the adverse effects of restraint and communication. The importance of fostering an attitude of understanding rather than of control was also echoed by Kolanowski et al. (2010). The researchers conclude that staff education can increase knowledge, change attitudes and reduce the use of physical restraint without any change in the incidence of falls or the use of psychoactive drugs.

Another study compared the effects of an educational programme on four Norwegian care homes for people with dementia (Testad, Aasland and Aarsland, 2005). This study consisted of staff in two care homes attending a full day seminar followed by one day sessions of guidance per month for six months. The researcher rating the use of restraint did not know which homes were the ones where staff were receiving the programme. The programme focused on decision making and ways to avoid the use of restraint. The success of the programme was evaluated on the number of restraints used on residents and the level of agitation of residents in the care homes where staff were receiving the programme compared to those where staff were not. The researchers conclude that although the level of agitated behaviour remained unchanged or even increased slightly, the educational programme led to a significant reduction in the use of restraint in institutionalized elderly people with dementia thus improving the quality of care.

These two studies lend support to the claim that it is possible to care for people with dementia without resorting to the use of restraint. The outcome measures adopted in

these studies (i.e. the criteria used to determine whether or not the interventions were successful) and the way that the results of these are interpreted are a positive reflection of the attitudes of the researchers towards the use of restraint. They suggest that the main objective of good care is not to rule out totally the possibility of falls or to reduce the occurrence of agitated behaviour but rather to provide humane, appropriate care which contributes towards the quality of life of residents. The educational programmes did not result in zero use of restraint although it is possible that this may result from continued exposure to this approach and on the ethos of the various homes. In the second study, a visit one year later revealed that staff were still carrying out the non-restraint programme.

Issues linked to the cost and organisation of restraint free practices

There is some difference of opinion concerning the cost of implementing restraint free alternatives (Wang and Moyle, 2004). Werner et al. (1994) stated that it is a complex and costly process, whereas Cohen et al. (1996) and Koch and Lyon (2001) argue that most alternatives are inexpensive, that additional staff are not required and that success is grounded in staff education and the commitment of staff, residents and families. In a qualitative study involving a series of focus group discussions with 35 staff members from six nursing homes in America, time emerged as a key barrier to the use of non-pharmacological approaches to BPSD (Kolanowski et al., 2010). The researchers concluded that it was necessary to implement staffing patterns which give staff the time to make a difference in the care of people with BPSD.

2.2.2 Chemical restraint

People with certain forms of dementia such as Alzheimer's disease and dementia with Lewy bodies may be prescribed "anti-dementia" drugs such as donepezil, galantamine, rivastigmine and memantine. For many people, such drugs slow down the progression of symptoms and improve their cognitive abilities for a certain period, thus contributing towards quality of life. They are therefore often described in positive terms.

In addition, many people with dementia are prescribed other types of drugs such as sleeping tablets, tranquillisers and anti-depressants to treat the symptoms or behaviour which may arise during the course of the disease (Jacques, 2001). Concern is increasingly being expressed about the use of these drugs for people with dementia. Some of these drugs are used to treat the behavioural and psychological symptoms of dementia (BPSD) and are commonly called "anti-psychotics". They date back to treatments originally produced in the 1950s as a treatment for psychosis which involves the inability to distinguish between reality and imagination. They are known as typical antipsychotics and include drugs such as chlorpromazine, haloperidol and trifluoperazine. Progress was made in the following decades resulting in a new type of antipsychotic drug becoming available in the 1990s known as an atypical antipsychotic (examples including risperidone, olanzapine and quetiapine), which had less disturbing side-effects. It is this second type of antipsychotic which is frequently given to people with dementia (Banerjee, 2009) and has come to be associated with chemical restraint.

Some experts believe that such drugs are not appropriate for people with dementia at all, whereas others believe that there may be situations which justify their use provided that other non-pharmacological approaches have been tried first. It is increasingly being recognised that antipsychotic medication should never be used as a routine measure. These debates have implications for the way that chemical restraint is defined in that most definitions of chemical restraint focus on the inappropriate use of medication and hence on the purpose of the administration of a pharmacological substance:

“Chemical restraint means a drug used to control behavior and used in a manner not required to treat the patient’s medical symptoms” (Title 22 of the California Code of Regulations).

“A psychopharmacological drug (a drug prescribed to control mood, mental status, or behaviour) that is used for discipline or convenience and not required to treat medical symptoms or symptoms from mental illness or mental retardation that prohibit an individual from reaching his highest level of functioning” (Virginia Department of Health, 2004).

“The use of drugs and prescriptions to change people’s behaviour” (Commission for Social Care Inspection, 2007).

“Sedative or tranquillizing drugs for purely symptomatic treatment of restlessness or other disturbed behaviour” (Mental Welfare Commission for Scotland, 2006, p.20) [adding that drug treatments for medical or psychiatric conditions which underlie the disturbance are not included].

Clearly, intention/purpose is important as a drug which is used in an appropriate manner and in the appropriate dose if and when required for the benefit of the person concerned would not be considered as chemical restraint. On the other hand, there are differences of opinion as to what constitutes appropriate use, an appropriate dose and the need for the drug to be taken. Some would argue that the use of antipsychotic drugs is not the appropriate treatment for BPSD and does not effectively treat medical symptoms due to the risks and side effects linked to its use. This will be discussed further in subsequent sections of this report.

Prevalence and use of chemical restraint

The prevalence of psychoactive medication in the context of long-term residential care of the elderly is quite high (Meyer et al., 2008;). A comparison of the use of chemical restraint in 31 specialised dementia units and 32 traditional units housing a total of 625 people with dementia was carried out in America. It was found that 45.3% and 43.4% respectively of people with dementia in the two units were being given such medication on a routine basis (Sloane et al, 1991). In Germany, over fifteen years later, an observational study of 30 nursing homes with 2,367 predominantly female residents in Hamburg found that 52.4% were receiving at least one psycho-active drug (Meyer et al., 2008). However, there is some evidence that the use of anti-psychotic drugs may be declining. A national audit of nearly half of all general practitioner (GP) practices in the UK revealed that the prescription of antipsychotic drugs to people with dementia In the UK, fell from

17% to 7% between 2006 and 2011 (Kmietowicz, 2012). On the other hand, it was also found that there were huge regional differences ranging from 2% in the London area to 13 % in the North West of England. Moreover, another study reported a stable use of anti-psychotics between 1990 and 1997 amounting to approximately 30% of cognitively impaired residents whereas 48% of 348 people with dementia were reportedly taking antipsychotics in three large cities in England in 2006 (Lindesay, Matthews and Jagger, 2003; Fossey et al., 2006). It is possible that there is some difference in the rate of prescription of such drugs across Europe and within individual countries. However, it is difficult to obtain generalisable and comparable data. A large proportion of people with dementia do not have a formal diagnosis of dementia but may be being prescribed antipsychotics (Banerjee, 2009). Similarly, some studies are not limited to people with dementia but cover all residents in nursing homes or cognitively impaired residents. Also, different methods of data collection are used such as self-report, observation and statistics from suppliers of the drugs or patients' records.

Common medical grounds for the prescription of various drugs to people with dementia

Chemical restraint is used as means of control and even punishment, sometimes to address staff shortages and sometimes due to lack of knowledge and skill to manage certain behaviours which are common in people with dementia, especially in residential care settings. Behaviour and mood, which are considered by others as being problematic or abnormal, are often considered as legitimate grounds for the administration of psychotropic medication but according to Banerjee (2009), antipsychotic drugs have only shown minimal efficacy for the treatment of BPSD. Benzodiazepines are also psychoactive drugs with a sedative effect. Their use is very common but poorly supported by evidence. On the contrary, there is evidence connecting them with cognitive decline, and increased frequency of falls and fractures.

As certain pharmaceutical drugs are commonly used to sedate people, there is growing concern over the "PRN" prescription of certain drugs such as psychotropics. PRN is an abbreviation of the Latin "*pro re nata*" (as needed) and means that a medical practitioner prescribes a drug which nursing staff may then administer to patients or residents at their discretion. Consequently, when the drug is actually administered (i.e. when it is later given to the person with dementia as opposed to when it is prescribed), it is nursing staff who decide. They are more directly involved in the care of people with dementia and therefore may be affected in their decision making by their own needs based on the behaviour of the person to whom they are administering the drug.

Medical impact and possible side effects of such drugs on people with dementia

Possible side-effects may differ slightly from one drug to the next but, according to Jacques (2001), might typically include:

- constipation, confusion, unsteadiness, low blood pressure and heart problems in the case of anti-depressants;
- loss of effect and dependency on the drug in the case of hypnotics or sleeping tablets and anti-anxiety drugs;

- tremor, muscle spasms (dystonia), restlessness (akathisia) and abnormal movement of the mouth and tongue (dyskinesia) and low blood pressure in the case of conventional anti-psychotics, as well as weight increase, sedation and unsteadiness in some of the atypical anti-psychotics, which nevertheless have relatively fewer side effects.

There is increasing evidence that the use of risperidone, olanzapine, aripiprazole and quetiapine is associated with a serious risk of adverse side effects, such as cerebrovascular adverse events (CVAEs), including death (Banerjee, 2009; Passmore et al., 2008). This has resulted in a series of warnings about the use of atypical anti-psychotics (e.g. from the US Food and Drug Administration (FDA) in 2003, the European Medicines Agency (EMA) in 2004 and the UK Medicines and Healthcare products Regulatory Agency in 2004) (Banerjee, 2009). More recent data (Trifiro et al., 2007) suggest that all antipsychotics, conventional as well as atypical, are associated with similar increased risk for all-cause mortality and cerebrovascular events. Subsequently the warnings were extended by the FDA (2008) and the CHMP (EMA, 2008) to include both types of antipsychotic drugs.

Risperidone is licensed drug for BPSD but with a strict indication, only for a short-term treatment (up to 6 weeks) of persistent aggression in patients with moderate to severe Alzheimer's disease unresponsive to non-pharmacological approaches and when there is a risk to harm to self or others. Olanzapine has also evidence that support its use but in the same concept and with caution. See also the Maudsley Prescribing Guidelines in Psychiatry (11th edition) for evidence-based information about the treatment of BPSD.

In a full consideration of the negative effects of antipsychotic medication, Banerjee (2009) points out that the findings of some studies may be misleading in the sense of underestimating the risk. This is because in an attempt to focus uniquely on the effect of the drug, the researchers may have chosen subjects who are not representative of the people who will eventually take the drugs being tested (i.e. the latter are likely to have more severe dementia, more general medical co-morbidity and hence be at greater risk in the first place of cardiovascular adverse events or death). As an example of the risk posed by the use of antipsychotics to people with dementia, Banerjee (2009) makes the following calculation:

"If, at any one time, we are treating approximately 180,000 people with dementia with antipsychotic medication in any year, and we make the conservative assumptions that the average treatment episode is the 6-12 weeks used in trials, this equates to the following: an additional 1,800 deaths per year; and an additional 1,620 CVAEs, around half of which may be severe." (p.29)

Ethical issues linked to the use of chemical restraint

Autonomy

The use of psychotropic medication without people with dementia having given their informed consent (i.e. either by concealing the medication, forcing them to take it or administering it without asking) fails to respect their autonomy. This deprives them of the right to decide whether to be treated.

In some cases, the behaviour of the person with dementia may be perceived as deviant in the sense of not fitting into the socially defined norm. This may result in treatment which suppresses their right to behave in a way which is congruent with their personality and feelings. Agreement that the person is acting out of character is not sufficient grounds to try to stop such behaviour. It cannot be presumed that everything that a person with dementia does is caused by changes in the brain. People react to the experience of dementia and to the way they are treated in different ways and having dementia may result in people being in different situations to those they may have experienced in the past. Also, their behaviour may reflect their emotional and psychological reaction to their symptoms and they have a right to express this. The issue becomes complicated when the person's behaviour greatly disturbs or offends other people. This creates a dilemma whereby it is necessary to balance the interests of all involved which is linked to the principles of beneficence, nonmaleficence and well-being. Even if the interests of other people are eventually given priority, this does not mean that the use of medication is justified.

Basson, Brugeron and Herson (2012) caution against the misuse of psychotropic substances as a kind of chemical straitjacket which deprives people of the possibility to express their wishes, thus making it easier for other people to decide on their behalf. However, they also reflect on the appropriate use of medication, including psychotropic drugs, to facilitate decision making. They give the example of a person who is anxious, depressed or delirious and therefore cannot apprehend a situation in an objective manner due to their emotional state and distorted perception of the environment. In such a case, they argue, the use of certain psychotropic drugs might allow for a smoother decision-making process involving rather than excluding that person. However, it must be considered whether the risks linked to the use of psychotropic drugs outweigh the possible benefit of participating in decision making, whether such a response is not disproportionate and whether other approaches might be more appropriate.

Well-being

Chemical restraint can interfere with the ability of people with dementia to communicate with others. This may have negative consequences on maintaining ties with loved ones, eventually leading to fewer visits. This, in turn, may contribute towards social withdrawal and isolation, and jeopardise relationships, which is not conducive to promoting the well-being of people with dementia. Moreover, apathy is generally considered as a cause for concern and not a state of well-being yet chemical restraint may lead to a state of being which is similar to apathy (e.g. a passive state, indifference and a blunting of emotions).

Respecting individuality

It is important to consider whether medication is the right/best response for the person with dementia: Often, behaviour is described as a behavioural or psychiatric symptom of dementia and attributed to neuro-degeneration. However, such explanations are increasingly being challenged along with the recognition that some of the behaviour which other people find difficult to manage is the result of frustration, boredom, fear

and self-expression of people with dementia. A more constructive approach to managing various behaviours, which are considered as problematic (often to other people), is to try to understand what the person is communicating through that behaviour as it may be a problem or unmet need which can be addressed (Kitwood, 1997 – in Hughes, 2008). Some behaviours, such as repetitive or continual walking (often called “wandering”) would be better understood rather than stopped (Marshall and Allan, 2006). There is growing recognition of the need to find other ways to manage such “symptoms” or behaviour. For this reason, what might have been considered as routine treatment a few decades ago is considered as a form of restraint. Alternative terms currently used (such as “chemical cosh”) reflect this gradual change in perspective.

In the context of the “users and survivors of psychiatry” movement, Minkowitz (2006) advocates the right to be different and for differences not to be the object of attempts to change a person from one state of being to another against his or her will. This could also apply to people with dementia who may be subjected to chemical restraint in order to make them calmer, passive and easier for others to “manage” rather than simply permitted to be as they are. Even in the presence of psychotic symptoms (feelings of persecution, delirium and hallucinations), the use of drugs is not necessarily the best option. Other options are possible. Other symptoms such as “wandering”, agitation and anger do not always even need to be stopped (Basson, Brugeron and Herson, 2012).

Beneficence and necessity

A key issue with regard to the use of medication is whether it is necessary and in the best interests of the person with dementia. If it is, it would be ethical to prescribe or administer it but if not, it could be perceived as a means of restraint.

It would be unethical to prescribe any kind of medication to people with dementia if the need for such medication had not been accurately assessed and established. However, many GPs receive very little training in dementia and are not confident in their ability to manage and treat people with dementia (Commissioning Support for London, 2009; Koch and Iliffe, 2010). This problem is often exacerbated by the short duration of consultations and difficulties communicating with people with dementia (Banerjee, 2009; Boise et al., 1999; van Hout et al., 2000).

Based on a review of the literature on agitation, Bidewell and Chang (2010) point out that there is no agreed, coherent definition and measurement of agitation. They argue that despite the existence of reliable tools to measure agitation, they are often time consuming and consequently, there is a tendency to ask for caregiver reports which may be prone to bias. They consider models of agitation based on biological and unmet needs, as well as on behavioural and environmental factors, which suggest the need for non-pharmacological approaches to dealing with agitation.

Proportionality

Psychotropic medication may have a considerable impact on the body and mood of the recipient. The issue of proportionality is therefore particularly relevant. It is necessary to

consider whether such a measure can be justified as a means to address an issue such as agitation for which a range of alternative options are possible with fewer and/or less serious side effects or consequences. In other words, is the use of psychotropic medication the appropriate level of intervention for the identified need?

Justice/equity

The prescription of anti-psychotic drugs with serious side effects to people with dementia has been long accepted and only begun to be challenged in recent years. In addition to the medical arguments against this practice, based on the serious side effects and the ethical issues of autonomy, beneficence and nonmaleficence that this practice raises, there is also the issue of justice/equity. It is unjust to expose certain groups in society to more risk than would be acceptable for other groups. One might consider whether it would be acceptable to manage certain behaviour or symptoms of other groups of people by administering psychotropic substances on a regular basis. It is clear that this would not be acceptable in the case of infants who are particularly prone to crying or screaming or of hyperactive toddlers. The fact that this is still the response to managing the behaviour or challenging symptoms of people with dementia is perhaps a reflection of ageism or of the stigma of dementia, both of which involve devaluation and discrimination.

Covert administration of drugs

Often, people who are in hospital are given one or more tablets and not told what they are. Some people, including those with dementia, may take the tablets based on trust or obedience (i.e. doing as they are told) and implicit consent might be assumed, whereas others may ask for clarification and thus take them on the basis of informed consent, presuming that they are capable of giving informed consent (which may not be the case). Whilst such medication is given openly, there may be an element of psychological coercion based on unequal power relations between medical professionals and patients (McKillop, 2013). Nevertheless, in both cases, the person is aware that they are receiving some kind of medical treatment. This is not the case when medication is administered covertly. This can occur in care homes, hospitals and even in people's own homes.

Crushing tablets or opening capsules (e.g. to disseminate in food or drink) may be harmful and therefore fails to respect the principle of nonmaleficence. Nurses who do this may be held accountable and prosecuted for negligence. Informal carers may be unaware of the dangers involved. Attempts to hide medication or alter its current form occur for a variety of reasons (e.g. due to a person's refusal of the medication, their tendency to spit out tablets, difficulties swallowing, dislike of the taste or not understanding what to do with the tablet when administered). Irrespective of the reason, there are risks involved which are linked to the formulation of the medicine. For example, some drugs are specifically designed to prolong the time taken to be absorbed in the body or to deliver the drugs to a particular part of the gastrointestinal tract (Greenwall, 2003). This is achieved by the coating of the drug. Enteric coating, for example, does not dissolve in acid and is therefore released in the intestine rather than the stomach. Osmotic coating, on the other hand, allows water to pass through it which results in a slow release. Another

option is coated beads for which a thicker coating results in a longer release time. Such tablets must therefore be swallowed whole in order to be absorbed as needed. Crushing tablets or opening capsules may therefore result in an initial overdose of the medication followed by a period with no medication. It is not always possible to know whether a drug has a modified release system.

With the covert administration of drugs, the respect and dignity of the person with dementia is at stake in that administering drugs in this way involves deceit and the betrayal of the trust that the person with dementia places in those responsible for their care and well-being. Such practices may jeopardize the trust that they place in professional or informal carers in other respects. It may also result in distress and anxiety if the person experiences side effects and cannot discuss them openly with medical staff as the latter are not admitting that a drug has been administered. Alternatively, the person may fail to mention disturbing side effects and simply attribute them to their condition.

Covert drug administration also fails to respect the principle of autonomy because, as mentioned earlier, it does not give a person the opportunity to give informed consent or refuse the medication administered. The person is disempowered as they are not aware of what is happening and are thus denied the opportunity to react. In concealing the administration of a drug, medical staff are subjecting the patient to possible side effects of various degrees of severity without their agreement.

The Royal College of Psychiatrists Ethics Sub-committee states that the practice of disguising medication in the food of patients who are unable to consent is unethical and should not take place (UKPPG, 2006). The Sub-committee makes a distinction between a deceitful process and a co-operative process for patients who find taking tablets difficult. Administering drugs in food is not considered unethical in the case of a person who is unable to consent provided that the decision has been discussed within a multi-disciplinary team and with relatives and carers and the person's advocate if there is one, that the decision is recorded and a doctor has prescribed the administration in this way. The person must nevertheless be informed each time that medication is administered in that way that it is in the food, which medication it is and why they are receiving it.

2.2.3 Zero tolerance of the use of physical and chemical restraint

Based on a reflection about the ethical issues linked to the use of physical and chemical restraint, there seems to be little if any justification for its use with people with dementia. Yet, it is persistently used throughout Europe. Alzheimer Europe is opposed to the use of all forms of restraint on people with dementia. Whilst accepting that there may be exceptional circumstances or isolated incidents which justify its use, this is considered unlikely and the rare exception to the rule. The working group was therefore very pleased to hear from Dr Antonio Burgueño Torijano about the "Untie the Elderly and People with Dementia Programme" in Spain (of which he is the Director). He argues in favour of zero tolerance of the use of physical and chemical restraint on people with dementia and looks at its prevalence in Spain. He explains how reasons frequently given for the use of restraint are not supported by empirical research and constitute popular myths.

Drawing on an extensive review of the current literature on restraint, a consideration of the ethical issues involved and over three years' practical experience of zero tolerance of restraint in Spain since the start of the programme in 2003 (based on fieldwork and data from 687 facilities and 29,332 residents), Dr Burgueño Torijano presents a convincing argument comprised of ten key points which describe why restraint is unethical and poor clinical practice, how zero tolerance of restraint can be practically achieved and the benefits of this approach for all concerned. Part of the philosophy of zero tolerance is the acceptance of a certain degree of risk and restraint is not considered an option except in rare situations where there is a serious and imminent threat to the integrity of the person with dementia.

The term "zero restraint" should be considered as an attitude rather than as a goal or the description of the outcome i.e. total absence of the use of restraint. When talking about restrictions on people with dementia, discussion arises about the use of psychotropic drugs. Some clarification is therefore needed regarding the term "zero tolerance". The proposal of a zero tolerance attitude to the use of restraint is not a zero tolerance of the use of psychotropic drugs but a zero tolerance of the use of these drugs for purely restrictive purposes. There are authorised indications of psychoactive drugs. As described earlier, in certain situations, this may be justifiable and in keeping with good care. Psychotropic drugs are part of the essential medical tools used by doctors to manage certain problems and in some cases are justifiable (i.e. when their use is appropriate, effective, clinically justifiable and proportionate to the perceived need, and not prescribed or administered on a routine or prolonged basis). According to Dr Burgueño Torijano, establishments which remain restraint-free are obliged to keep a tight control of the use of psychotropic drugs and polypharmacy, and to enhance the environmental and organisational measures to prevent falls and serious behavioural problems (as can be seen in Appendix 1, the inappropriate use of psychotropic drugs may result in the use of physical restraint). He maintains that this can only be achieved and maintained by means of an attitude of zero tolerance. In order to implement zero tolerance, professionals need to be well trained and able to act within the framework of a special management policy within the facility and in a supportive context. The Spanish programme was therefore created to serve as a reference. It provides a technical framework, performing outreach activities, training and recommendations etc. The accreditation system of restraint-free facilities in Spain, developed by the Untie Programme, has resulted in greater public awareness of restraint-free facilities. The full text of this argument can be found in Appendix 1.

Measures to rule out or limit the use of restraint can also be found in other countries. In the Netherlands, for example, the focus is on using fewer restrictions of freedom and the Health Care Inspectorate monitors progress with this. According to Frederiks (2013), zero tolerance policy involves much more than informing carers that the use of restraint is no longer permitted. A zero tolerance policy involves supporting management, raising awareness of carers and providing training to improve their expertise etc. This is essential to avoid the creation of new problems which might lead to an increased use of medication. This point is echoed by Burgueño Torijano who states that an attitude of zero tolerance is required in order to prevent new problems from occurring. However, there

are cultural and also legal differences in the definition of restraint. In the Netherlands, for example, all psychotropic drugs, irrespective of their indication, must, due to recent changes in legislation, be considered as a form of restraint (Frederiks, 2013). This may also be the case in some other countries.

2.2.4 The use of force/physical intervention

People with dementia are sometimes physically restrained not through devices, equipment or chemicals but by means of hands-on contact. This presumably occurs when other people cannot manage a difficult situation and lack the skills to communicate with the person with dementia. The use of force might, for example, include pushing or pulling a person (e.g. into a van, building, chair or bed), grabbing hold of their arms to force them into a particular place or prevent them from leaving or pinning them down or immobilising them (e.g. in order to administer treatment or “care”). Physical violence might also be used such as slapping, hitting or shaking the person. This would also be classed as abuse and violence, as might any illegitimate use of restraint. As stated earlier, the use of restraint can rarely be considered as being legitimate. In some countries, legislation addressing abuse or violence contains special reference to potentially vulnerable groups such as older, dependent people and people with mental or physical disabilities. Sentences are often more severe in the case of abuse against a person for whom one is legally responsible for their care. The moral justification for the increased sentence perhaps reflects the moral obligation of solidarity and care towards people who are less able to protect themselves.

2.2.5 Coercion

Coercion involves the use of threat, intimidation or another form of pressure to force another person to do something that they would not do by choice. Again, this does not necessarily involve the use of devices or chemicals. Coercion may involve the infliction of physical or psychological pain or pressure but sometimes a credible threat may achieve the desired result. Often the initial use of force is what makes future threats credible. In other cases, the threat is based on deceit as the thing that is threatened could not occur but the person does not know this.

The use of coercion is relevant to the principle of autonomy as it involves denying a person the right to determine their own actions. It also reflects failure to respect a person’s dignity and the abuse of power. The principle of nonmaleficence is not respected as coercion may result in significant psychological and even physical harm. Allowing coercion to occur represents a failure to protect people with dementia from harm.

In nursing homes, people have limited opportunities to deal with the situation. They have nowhere to go and in many cases cannot avoid contact with the person exercising coercion. They may also feel powerless in that there is an unequal power relationship between residents in a nursing home and care staff. In care homes, certain power relations may in some respects differ from those common in society at large and in other respects be similar. For example, people from ethnic minority groups may find themselves in a position of power over residents from the dominant ethnic group in

that society (although not necessarily within the professional hierarchy). Other forms of pre-existing unequal power relations may nevertheless affect the experience of coercion (e.g. the use of coercion by male carers against female residents/patients). This also applies to the use of physical restraint in general. The life history of each resident/patient is not always known. People with unresolved psychological trauma, a history of physical abuse or having experienced abusive relationships may be more deeply affected by coercive measures than others.

The problem may be further exacerbated by the fact a person with dementia may have difficulties communicating and their credibility may be questioned. In nursing homes with poor standards where staff lack appropriate knowledge, certain coercive practices may even be tolerated or promoted by the management.

2.2.6 Environmental restraint

Environmental restraint would cover measures to restrict the freedom of movement of people with dementia by means of adaptations made to the living environment. Examples might include:

- locking devices (either mechanical locks, code-operated locks or complicated opening mechanisms which people with dementia might find difficult to operate);
- staircases with no handrail;
- poor lighting;
- confusing colour contrast on the floor;
- mirrors on doors to make people think there is someone else there;
- lack of transport.

Debatable/depends on circumstances:

- camouflaged exits (e.g. using a curtain, a continuing barrier along a wall or signs);
- walking areas which all lead back to the point of departure;

The above examples raise a few different issues. The first example could be construed as consisting of the unlawful restriction of liberty if used, for example, in a person's home or day care centre which people voluntarily attend. Voluntary residents with dementia can sometimes be seen at the door of a day care centre, frantically beating on it with the hope of being let out. Sometimes, people with dementia beg visitors to let them out so that they can go home. This can be heart-breaking. They are clearly not enjoying the freedom and security to move about in a restricted area. Staircases with no handrail and poor lighting are dangerous especially for older people with dementia who may be unstable on their feet. Also, people with dementia may have problems with visual perception and tend to need more light than usual. Confusing colour contrasts on the floor may make people with dementia uneasy or even stumble (e.g. if the contrast appears like a hole or a step). Lack of transport forces people to stay where they are, especially if the amount of money they are permitted to carry about has been limited so that that they

cannot get a taxi or bus. This is especially problematic in places which are situated at a considerable distance from towns. It means that people are not free, for example, to go for a drink in a pub or to a betting shop, the hairdresser's or a cinema.

Nowadays, camouflaged exits and circular walking areas are generally considered as good dementia design but if not used appropriately may serve as a means of restraint. For example, whilst some people may enjoy ambling around the building, perhaps talking to other residents, or getting some fresh air in a garden in the security that they will find their way back, others may feel trapped. Circular walking areas enable people with dementia the freedom to move about freely and in security but only within the area to which they have been granted access. Some public buildings, such as such town halls, churches, museums and educational institutions, also prevent people from entering private areas. Nevertheless, people in such places have the freedom to leave the building, whereas this is often not the case for people with dementia. People with dementia are not only being denied access to certain areas but also of the right to leave the building. Used in an appropriate care context and for the individual needs of people with dementia, certain measures (such as camouflaged exits and circular walkways) could be considered ethical in the sense that they provide a safe environment, give people the opportunity to exercise and may encourage social interaction. Staff therefore need to be attentive to how various design features are experienced by individuals and to be ready to intervene when necessary.

Environmental restraint therefore touches on a wide range of ethical issues, covering respect for people's autonomy, what benefits, disturbs or harms them and whether it is justified to use such measures. The concepts of singularity and historicity are also important as environmental restraint is usually a global approach for which differences between people cannot easily be taken into account.

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. The failure to respond to the needs of people with dementia outside of the home and to take into account their impairments results in a loss of mobility and hence of freedom to choose where to go and what to do. Loss of such freedom may result in social isolation, depression and premature loss of remaining skills. The environment in this case consists not only of the physical environment but also of attitudes and practices within the public domain which serve to restrain people with dementia.

2.2.7 Psychological means of restraint

Deceit has already been mentioned in relation to the use of coercion and the covert administration of medication. It is also an unethical psychological tactic used to prevent people from moving about or leaving a building or area which involves taking unfair advantage of a person's cognitive impairment. A typical example is the situation whereby a person is led to believe that someone is coming soon to pick them up (e.g.

from a day care centre). They then spent all day by the door waiting for that person or van to arrive and take them home. Not only do they miss out on the opportunity to carry out enjoyable activities (if there are any available) but they may worry about missing the person and being left there. Meanwhile, staff have peace of mind in that they know where the person is and what they are doing (i.e. waiting). There have even been cases, where a mock bus stop has been created for that purpose. The person can sit down and occasionally go back inside for a cup of tea whilst waiting. It could be argued that this reduces distress but at the same time it could be considered as disrespectful, amounting to a mockery of the person. Whether such practices are disrespectful depends to some extent on how they are implemented. If the bus stop, for example, becomes a place for social interaction where people sit together on a comfortable bench, protected from the wind and rain, and chat or look at pleasant surroundings, the effect may be beneficial despite the fact that it is misleading. If people are left to stand alone at a solitary post in a state of distress and expectation, it cannot be said to be beneficial in any way.

The use of deceit may also have more far-reaching consequences in that it may deprive a person of their freedom and result in them losing their home, their belongings and their social contacts. This is the case, when a person is tricked into believing that they are going into respite care for a short time when in reality they are being moved into residential care. Their cognitive impairment renders them particularly vulnerable to such trickery.

Other psychological means of restraint include the use of emotional blackmail (which would also be coercion), false promises and measures which challenge a person's self-esteem and dignity such as ridicule, infantilisation, objectification, ignorance and humiliation. For example, a care worker may complain loudly when asked by a resident to be accompanied to the toilet thereby drawing attention to a private issue or using childish terms which are belittling. This might result in the person restricting what they drink to avoid the embarrassing situation or suffering in silence, remaining seated and risking incontinence.

The power of the white coat may also serve as a psychological means of restraint. Some people, including those with dementia, tend to defer to doctors and may therefore comply with restrictive measures which are not necessarily in their best interests simply because they have been ordered by a doctor. Such deference may be based on courteous respect or difficulty challenging the perceived authority of doctors.

Cultural norms and procedures are sometimes also used against people to prevent them from doing what they want. This might be based on pride in one's appearance, common practice or respect for others. For example, ensuring that a person spends the whole day in nightwear, does not have access to their traditional headdress or only has slippers may be sufficient to prevent some people from leaving a building despite being free to do so. For example, some people would not go out in public without covering their head or body in accordance with their religious beliefs and traditions although many would wish to wear such attire indoors as well if other people were present. Some people might

willingly do what others want to avoid getting another person into trouble. Others may adhere to restrictive rules and regulations as they have come to believe that they are not worthy of the freedom that other people enjoy or feel a burden to society.

Freedom of movement and choice can also be limited by attitudes and practices which provoke psychological or cognitive responses such as shame, confusion, anxiety or fear. This is particularly reprehensible bearing in mind the memory loss and confusion often experienced by people with dementia. In some cases, this could also be perceived as intimidation tactics/coercion, as illustrated in the following example.

“One staff member prevented some people moving around by placing their hands on their Zimmer frames and asking several times where people were going, which resulted in some people looking anxious and submissively sitting back down.” (CSCI, 2008 cited in Hughes, 2008)

2.2.8 Assistive technology

Although assistive technology (AT) can be used to facilitate independence within the home or in residential care settings, and for communication, well-being and recreation, its use for surveillance and monitoring often receives most attention in relation to ethical issues as it tends to be associated with the restriction or loss of freedom. However, whilst surveillance and tracking devices can be used to restrict freedom, they can also be used in an ethical manner to promote autonomy and increase freedom (Niemeijer et al., 2010; Zwijsen et al., 2012). Examples of surveillance and tracking devices or systems include:

- the direct tracking of a person by means of global positioning systems (known as GPS) which locate a person by satellite (due to an ankle or wrist device, a pendant or a mobile phone) and then transmit details of their 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 their 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 “bread crumbing”).
- 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.

It has been suggested 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). In the context of residential care, debates over the ethical

issues linked to the use of AT tend to focus on the moral acceptability of the effects of its use, with conflict often arising when the interests of institutions do not correspond with those of the residents.

A major issue related to the use of the tracking and surveillance devices is that of balancing autonomy and freedom of movement with concerns about safety and the possible need to protect people with dementia. Tracking and surveillance devices can be seen as contributing towards autonomy by enabling people to go out alone or move about freely without having to ask permission. It gives people the freedom to decide when and where to go (sometimes within certain established or agreed limits). This may help maintain morale, self-esteem and social contacts, provide exercise and generally improve quality of life. Those which monitor movement may enable people to get along with their daily lives in relative privacy but with the assurance that assistance is possible if and when needed.

Zwijsen et al. (2012) describe how surveillance technology can be used as a means to provide general safety, additional safety or more freedom. They highlight its limitations such as it not being able to prevent falls, not guaranteeing quick help, not always working properly and violating privacy. However, it is clear that it can be used constructively as one measure within an overall approach to care. The issue of privacy can also be addressed, assessed in relation to alternative approaches and attempts made to minimise the impact of the use of surveillance on privacy. Some loss of privacy might be preferred by some residents when compared to potential gains in freedom of movement (e.g. a preference for movement monitor or even a video camera in a bathing area to enable a person to bathe alone).

On the other hand, the same devices may be perceived as a means of restriction with an over-emphasis on safety (perhaps influenced by fears of litigation amongst professional carers), or a form of coercion or social control (preventing people from carrying out certain activities) and may lead to frustration and increased dependency on others. The principles of beneficence, nonmaleficence are important in this respect. There are also issues of privacy and dignity to be considered, and the risk of paternalism and of stereotyping people with dementia as vulnerable (i.e. applying a blanket label of "vulnerable" rather than assessing the possible vulnerability of each person in relation to a specific situation).

The way that AT is experienced depends on many factors (in addition to the needs and wishes of each person with dementia) such as the framework in which it is used, people's individual judgements of its benefits, risks and drawbacks, the meanings they attach to it, its visibility and aesthetic qualities, and the extent to which users have been consulted and consented to its use. The ethical issues linked to this topic were discussed in-depth in a report published by Alzheimer Europe in 2010 and will therefore not be repeated here. They can be consulted at:

<http://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice/The-ethical-issues-linked-to-the-use-of-assistive-technology-in-dementia-care>

2.2.9 Recommendations on the freedom to live in the least restrictive environment

Government, policymakers and service providers

Policymakers and service providers should strive for the least-restrictive environment for people with dementia.

Allocation of resources at all levels should reflect the commitment to achieving least restrictive environments.

A legal framework and guidelines should be developed to protect people with dementia against the use of restraint.

An awareness raising campaign should be developed in order to inform people about the relevant legal and ethical issues linked to the use of restraint.

A definition of restraint should be included in the framework and guidelines which covers physical, chemical, psychological, electronic and environmental measures but is sufficiently broad to include any other measures which serve as a means of restraint through the way they are applied.

The use of restraint on people with dementia without informed consent should be considered as unethical and a form of abuse unless justification can be provided to prove the contrary.

The use of restraint on people with dementia, if personalised and respectful of each individual and of his/her unique situation and needs, may be considered as part of good care provided that the person has given informed consent.

An independent organisation should be established with responsibility for investigating the use of restraint to which people with dementia (and other residents in homes), carers and healthcare professional can report their concerns anonymously.

This organisation should be granted the power to make unannounced inspections, to issue recommendations to organisations to change their practices and take appropriate legal steps if necessary.

Governments should set targets to reduce the prescription of anti-psychotic medication for people with dementia.

Clear guidelines should be developed for doctors on the prescription of anti-psychotic medication for people with dementia, covering the dangers, possible alternatives to

dealing with BPSD and challenging behaviour and the need to reduce such prescriptions.

In cases where the police (or other relevant authorities depending on the country) might be called in to restrain a person with dementia or ensure his/her transferal to a care facility, they should have at least a basic understanding of dementia and take measures to minimise distress and discomfort linked to the use of any measures of restraint.

General

People with dementia should not be submitted to the use of restraint.

Restraint should only be tolerated in extreme situations where the physical and mental integrity of the person with dementia is in serious and imminent danger.

Such situations are considered extremely rare and should be avoided by careful planning and reflection.

The restraint of a person with dementia who is unable to consent should be permitted only after discussion within a multidisciplinary care team and with the relatives, carers and advocates of the person with dementia.

The use of restraint should not be considered an option but rather a failure on the part of carers to provide good care.

A person with dementia who has been physically restrained should not be left unattended.

Restraint should never be used on a routine basis even if initially prescribed by a doctor.

Before considering how to deal with BPSD and challenging behaviour, it should be determined for whom such symptoms and behaviour are disturbing.

The use of any form of restraint should be authorised by a doctor and documented.

Failure to obtain medical authorisation for the use of restraint should be considered as a negative factor in inquiries into suspected abuse linked to the use of restraint.

Medication should not be concealed in the food or drink of a person with dementia who is able to consent to drug treatment unless they have given such consent.

Whenever medication is administered through food and drink, the person receiving it should be informed and provided with the reason for this approach as well as details of the medication administered in that way.

Care establishments

Care establishments should develop a clear policy about not using restraint.

Care establishments should develop and implement a policy of zero tolerance of restraint.

Care establishments should support healthcare professionals in providing restraint-free care.

Care establishments should ensure that measures of restraint are not readily available to personnel who provide care or treatment to people with dementia.

Care establishments should ensure that the demands of the organisation with regard to the provision of care do not encourage care staff to restrain residents.

Care establishments should discuss with the carers and relatives of residents with dementia the need to promote autonomy and of the necessity to allow some degree of risk.

Care establishments should have a clear policy for dealing with possible injuries which residents may suffer in the course of their stay, including responsibilities in possible cases of litigation.

Healthcare professionals

Healthcare professionals should receive training in the use of non-pharmacological interventions to deal with BPSD and challenging behaviour.

Doctors should be obliged to justify that any prescription of psychotropic medication is appropriate, effective, clinically justifiable and proportionate to the perceived need.

Doctors should ensure that any prescription of psychotropic medication is time limited.

Doctors should consider whether BPSD and challenging behaviour are caused by other factors which might require specific treatment or non-pharmacological approaches.

Psychotropic medication should never be prescribed or administered on a routine basis.

The appropriateness of the prescription for any person with dementia already taking antipsychotic medication should be reassessed.

When psychotropic medication is administered on a PRN basis, the reason for administering it at a given time should be documented, as should the initial prescription.

Healthcare staff and doctors prescribing or administering psychotropic medication to people with dementia should ensure that the potential benefits outweigh the risks for each person receiving them and be able to justify this.

Healthcare professionals should be informed about the risks involved in using restraint on older people and people with dementia.

Healthcare professionals should receive training on how to reflect on the ethical issues linked to the use of restraint.

Healthcare professionals should be informed about the ethical and legal implications linked to the provision of care as well as to the use of restraint.

Informal carers

More research should be carried out into the use of restraint at home.

Informal carers should be informed about the legal and ethical issues linked to the use of restraint.

Informal carers should be provided with training to deal with BPSD and behaviour which they may find challenging.

Informal carers should have access to affordable, appropriate and timely support as well as respite in order to address issues which might lead to the use of restraint.

2.3 The restriction of the freedom to act according to individual attitudes, values and lifestyle preferences

The freedom to act in a way which is consistent with individual attitudes, values and lifestyles may be threatened when a person has dementia, especially if they move into residential or semi-residential care. They may find that they are more or less obliged to adapt to the way of life of the institution which is influenced by the values and ethos of that institution and by the attitudes and values of the people who are employed in it. However, self-expression is also an expression of autonomy and closely linked to respecting personhood. It is about people's emotions, how they feel about themselves and their lives, what they want and their well-being. It is not dependent on the ability to make a rational decision (Nuffield Council on Bioethics, 2009).

In this section, we discuss the ethical implications of not having the freedom to continue living in one's own home. We then consider the kind of restrictions which people may experience in residential and non-residential care settings in terms of freedom of choice and self-expression, and the ethical issues that such restrictions raise. Finally, we describe the ethical issues linked to attitudes and practices regarding the freedom of people with dementia to enter into relationships and to express their sexuality.

2.3.1 The right to live in the community versus social segregation

Most people with dementia live alone, with relatives or partners or in residential homes. Some live in religious institutions or prisons or are travellers or homeless but very little is known about their living arrangements and about the provision of services to people

with dementia in these groups. Depending on opportunity and financial means, some people would prefer to live amongst others in a residential setting with round-the-clock care, support and security. Some would not.

Family patterns are changing in that more women are professionally employed compared to previous generations. Even though the vast majority of informal carers are female (i.e. wives, daughters and daughters-in-law), in some countries there is a move away from the expectation that they will care for their ageing parents. The gender difference in the provision of care to older people is much lower for older people as men provide as much care as women when it is to their elderly spouse (Hoffmann and Rodrigues, 2010). However, this only applies to the older age groups. Whereas in the past, it was common for different generations of the same family to live together, this is less common nowadays. The projected support ratio of women aged 45-64 (the age group most likely to provide informal care) for each person aged 80 and above has diminished in the last 15 years in many Western European countries.

In most countries, there is an assumption that the spouse will take care of their partner with dementia. In some, such as Austria, the principle of subsidiarity (Subsidiaritätsprinzip) operates which means that there is an order for financial responsibility for care: 1st the family (including adult children), 2nd the commune, 3rd the provincial state (Land) and finally, the State. The right of the spouse or adult child to decide whether or not to become the carer of the person with dementia is rarely taken into consideration. In a survey-based study into the experience of care involving 585 carers in ten European countries (including Norway and Iceland), 50% of female and 35% of male carers strongly agreed that they had “drifted into care” (Alzheimer Europe, 2001). The two most common responses to an open-ended question about factors affecting the decision to become a carer could be summarised as reflecting duty/responsibility and having no choice or alternative.

Some people with dementia find that they (or their relatives or partners) can no longer manage daily life due to the consequences of dementia and some have no relatives or close friends to provide care for them. These people may eventually move into residential care reluctantly or against their will because the state does not provide the necessary amount of care to enable them to stay in their homes. This results in a loss of freedom (i.e. the freedom to live and participate in the community, the right to liberty and freedom of movement, the freedom to choose the kind of care arrangements they would like and the freedom to choose with whom they will live and associate). This fails to respect their autonomy and singularity, as well as the principle of beneficence and justice.

Similarly, informal carers who look after a person with dementia at home, but do so as they feel that they have no choice, have also not decided freely. For some, this might reduce their freedom to pursue a career, to enjoy their social life and to fulfil certain plans. In both cases, one or more people experience a restriction of their freedom due to a lack of adequate or appropriate support from the State.

The question is “to what extent is it the State’s responsibility to provide such care and support?” As explained above with regard to the principle of subsidiarity, some countries have an order of responsibility which includes the State. In many, there is limited state support specifically for people with dementia and the kind of care and support provided by the State is often inadequate and inappropriate (Alzheimer Europe, 2007). The Convention on the Rights of Persons with Disabilities (which includes dementia) covers the right to live independently and to be included in the community. Article 19 is particularly relevant.

Article 19 - Living independently and being included in the community

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b. Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c. Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

Source: <http://www.un.org/disabilities/convention/conventionfull.shtml>

This brings us back to the issue of reasonable accommodation which was discussed in section 2.1.1 with regard to involuntary detention. However, there are also issues related to subtle coercion. People who are capable of making a decision about their current or future care do so based on their wishes but also an analysis of relevant information. This includes weighing up the pros and cons of available options. If they find that affordable options do not exist to enable them to stay at home, they may opt for residential care. However, the fact that various options do not exist or are not available or affordable to them may be unjust (particularly in the light of reasonable accommodation). They may also be influenced in their decision by the perception of society’s view of people with dementia based on stereotypes and devaluation. Bursztajn and Brodsky (undated) suggest that people may disavow what they might actually want if they are conditioned to believe they cannot have it or should not ask for it. They add that older, chronically ill people are especially vulnerable to such demoralizing influences. Negative perceptions of dementia may result in lower expectations and a failure to challenge to current provisions.

The Mental Disability Advocacy Center (MDAC) (2011) suggests that States should take measures to phase out institutions and direct funds towards providing services in the community in line with the social model of disability. The Alzheimer movement in Europe tends to argue in favour of good quality residential facilities for people with dementia, as well as good quality home care and support in order to enable people to make real choices about their care and living arrangements. It is therefore not against residential care but against ill-adapted and inappropriate institutions. Some countries have large scale institutions in remote areas which do not represent good quality care but which are the only support available. Having institutions in remote areas represents a geographical but also psychological separation of people with dementia in that it facilitates their categorization as a separate group which is one of the components of stigma (Link and Phelan, 2001; 2006). In practical terms, the geographical distance may be detrimental to their well-being as it is more difficult for people to visit, especially for older people (e.g. the partners of the older people with dementia), many of whom have mobility problems and may also be unable to drive for health or other reasons.

In the Norwegian Dementia Plan 2015, it is stated that 80% of people in nursing homes have dementia and are living in nursing homes which were not built for or adapted to their needs. Their plan is to adapt such institutions and rebuild more in the form of small-scale communal living arrangements and wards with programmed activities and direct access to adapted outdoor areas, and to do away with old-fashioned multi-story institutions with large wards and long corridors (Norwegian Ministry of Health and Care Services, 2008).

Other countries have developed different approaches to residential care. Examples include the "Wohngemeinschaft" in Germany where people with dementia live together in a group living situation and bring in the support they need from outside as they would were they living alone in their own homes. Their place of residence is actually considered as a private home and not as residential care. Another example is "De Hogeweyk", an Alzheimer village near Amsterdam (Saxl, 2012). The setting reflects daily life, not only for people of Dutch ancestry but also of the many people of Indonesian origin who live in the Netherlands. However, the village, like many old-fashioned institutions, is located at a distance from the rest of the community. It does not constitute a dementia-friendly society but rather a dementia-friendly establishment. Measures to enable people with dementia to have the choice to remain in their own homes should focus not only on the provision of support at home but on changing attitudes and practices within society which make it difficult for people with dementia to live independently or with assistance.

2.3.2 Practices within residential and semi-residential care settings

The focus of this section is on the consequences of not having the freedom to live in one's own home. Irrespective of whether people with dementia move into residential care by choice or otherwise, they are likely to have to abide by the rules of the institution and to adapt their lives to the expectations, practices and rules of that institution. This represents a loss of freedom of choice and of self-expression.

The term “institution” will be used in this section to describe the place where people with dementia receive residential and semi-residential care. In most cases, this would be by paid staff but in some cases, it might be by volunteers or members of religious orders. The use of this term is in keeping with the use of the term “institutionalisation” to describe the process of moving into such long-term care establishments.

A major criticism of institutions is that they are impersonal, dehumanising and socially segregate people from their communities. It has also been argued that they violate people’s right to autonomy and threaten their dignity (MDAC, 2011). There is undoubtedly a huge difference between institutions in different countries, within countries and also between institutions for different categories of residents (e.g. people with learning disabilities, older people and/or people with dementia). There are also differences in how people define an institution. For some people, it might be a place where social welfare and accommodation is provided, for others a psychiatric hospital, a nursing home or a special Alzheimer unit. This section considers certain practices which restrict freedom in institutions. Some of the issues raised are taken from the work of Erving Goffman entitled “Asylums: essays on the social situation of mental patients and other inmates” (published in 1961) which were based on a qualitative study using observational methods. Goffman considered “total institutions” in the broad sense, not only as relating to mental institutions but also to prisons, armies, schools, monasteries and places “to care for persons felt to be both incapable and harmless” (Goffman, 1961, p.4). Some of his claims have since been challenged on the grounds that his work was negatively biased, contained over-generalizations/unfounded claims and was not supported by subsequent empirical data (Weinstein, 1982). Certain points may nevertheless be relevant to the situation of some people with dementia in some institutions.

Feeling “at home”

The term “home” is generally used to refer to a house, dwelling or other place of residence and a place that is dear to one or has some personal meaning. For some people, home is a village, town or region. In most cases, when adults talk about “home”, they are referring to a place which is private and personal even if they share it with other people (as usually they chose to live with those people). It is also generally considered as a safe place and a place of shelter from the wind, the cold, the rain and even the sun. In most cases, people feel “at home” there, they invest in that living space, personalise it and can behave differently than when they are in the public sphere. The home is an area where people can express their individuality, through the building and also through the way that it is furnished and the personal objects it contains (Charras et al., 2011a).

Even within the home, there are likely to be areas to which people can withdraw for more privacy. People can be themselves and relax in a way that is not generally possible outside the home. As it is their personal space, people tend to organise routines with their home and make their own rules. Most people help maintain their living area, taking care of it as it is personal and usually their responsibility even if they do not own it. Phrases such as “in the comfort of your home” and “make yourself at home” suggest that homes are comfortable places where you can relax and be informal. The criteria to call a place a

home, in which one can “feel at home”, might therefore be described as being: privacy, protection from the elements, safety, personalization, conviviality, informal, relaxation, comfort, responsibility, a place to be oneself and a place where one makes one’s own rules. The home is thus a physical as well as social environment (Moser, 2009).

These criteria do not necessarily apply to the establishments often called “homes” in which people with dementia live. These are places of communal living, organised in most cases by paid staff with or without medical or social training. Whereas most people feel “at home” in their own private homes and some in places which they have made their home, this is not always the case in residential, nursing or care homes. People in such homes sometimes lack privacy, the right to personalise their surroundings and the right to make decisions about life within the home. The presence of paid or even voluntary staff blurs the boundaries between formality and informality and between the private and public domain. The rules in a home, for example, may be formal, imposed and lead to sanctions whereas those in one’s own home tend to be informal, mutually agreed upon and more flexible. However, homes can be very different depending on how they are organised, the ethos of the home and mentality of the people who live and work there. This may also affect the extent to which people feel at home in them.

Freedom to go outside

A home is usually a building or part of a building but also often considered as extending to the area immediately surrounding it and even the community in which it is located. Some people with dementia do not have the opportunity to go out. Their whole world becomes restricted to a series of rooms and some of them may be confined within four walls. This represents social exclusion, is an infringement of the right to move about freely, fails to respect their human dignity, is an abuse of power and fails to make reasonable accommodation in order to enable people with dementia to benefit from the same rights as other people. In forcing people with dementia to remain indoors, they suffer from a lack of fresh air, exercise and sunlight, of contact with nature, the seasons and the weather and of interaction with a different set of people. The benefits of outdoor access and of people’s right to go outside have been recognised yet as Pietikäinen (in print) points out, that right is better enforced for prisoners than it is for people in nursing homes. This is clearly unacceptable. It is unacceptable to deprive people with dementia of this right even if they have been involuntarily detained.

Unequal power relations

In many institutions, there are differences between residents and staff in terms of the power to make and enforce decisions, as well as differences in living conditions. Power may be exercised at different levels by different members of staff and management. It may, for example, consist of controlling access to alcohol and cigarettes, controlling visits and purchases, requiring people to eat, sleep, wash and go to the toilet at set times and using chemical and physical restraint. People with dementia may lack the power to enforce their rights and preferences due to cognitive and physical impairments but also due to their perceived or actual lack of power.

Unequal power relations may be created based on how people with dementia in institutions are defined and how their presence in the institution is perceived. They may, for example, be considered as residents (a fairly neutral term), clients (which perhaps suggests an exchange whereby accommodation and care are provided in exchange for payment) or patients (which might suggest that the person has needs which must be met by others with the knowledge and expertise). The way that the care is financed and where it is provided may also affect how the person with dementia is perceived. In some countries, people with dementia are cared for in a range of institutions such as the geriatric department of hospitals, in old people's homes or in mental hospitals in Latvia, social houses in Bulgaria, government-owned nursing homes and care run by the Church in Hungary and Greece (Alzheimer Europe, 2007). There is therefore a risk that people with dementia in some forms of long-term care are perceived as social welfare recipients, mental patients or beneficiaries of charity rather than as equals with a right to be cared for. This may lead to stigmatisation and influence the expectations of people with dementia and care providers about the quality of care required and the power relationship between the two groups.

The fact that care providers have access to and control information about residents, including very personal details, and can observe them going about their daily lives, also creates a potential power imbalance. Residents' private lives become public but they have no information about the private lives of staff, unless the latter decide to share it. On the other hand, knowledge is needed about residents if staff are to provide care in an ethical manner, taking into account each person's values, experience of life, needs and preferences. Knowledge for the sake of knowledge is of limited value but taking the trouble to get to know a resident and taking an interest in their life out of genuine interest or concern about their well-being is a different matter.

Role dispossession

Goffman (1961) describes a process of role dispossession whereby, on entry into an institution, a person loses the roles they previously held. The roles that people acquire throughout their lives tend to be constructed around practices, within specific time-frames and in relation to other people. When a person is taken out of their familiar environment and away from the people they know, and when they are obliged to abide by different rules and schedule their day in a different way, it is difficult to maintain many of those roles. This may have serious repercussions on their well-being. The social roles we adopt are part of our identity and of what makes us unique. In the context of mental institutions, Goffman suggests that role dispossession is a deliberate process to sever the ties with the outside world and part of the process of depersonalisation intended to make residents more malleable. In nursing homes, one might imagine that this is not the case. Moreover, in the case of dementia the loss of social roles is often a gradual process which starts prior to and during institutionalization. However, there are anecdotal reports of relatives being asked not to visit people with dementia when they first move into residential care in order to allow them "to settle in". Whilst institutions cannot be held responsible for the gradual loss of social roles, they are responsible for practices and

procedures which unnecessarily contribute to that process as that would fail to respect individuality, dignity and beneficence.

Belittling or demeaning practices

The deliberate belittling or demeaning of residents would obviously be unethical and fails to respect their uniqueness and personhood. This could also occur in people's own homes as well as in residential care. It might also happen inadvertently through a lack of attention to people's feelings and through the careless implementation of certain procedures. Practices such as being obliged to ask for little things such as a cigarette or cup of tea, to use the telephone or go to the toilet, places people with dementia in a submissive position which is unnatural for adults and leaves them open to belittling attitudes and behaviours from others such as being teased, denied, questioned, ignored or put off (Goffman, 1961). Having to ask for various items may also be linked to residents having to use standard supplies (e.g. of soap, shampoo and even toilet paper), which itself fails to respect individuality. Asking for something that is needed is not demeaning *per se* but it becomes so if the person feels that it is unjust, that there is an implied lack of trust or that it is an abuse of power. In several psychiatric institutions and social care institutions in Croatia investigated by the Mental Disability Advocacy Center, it was common for residents not to have their own soap or toilet paper, and such items were sometimes rationed (MDAC, 2011). It is not known whether similar practices exist in institutions where people with dementia are cared for.

Belittling and demeaning practices are also closely related to dignity and privacy. Examples include supervising a person in the bath or in the toilet area when it is not strictly necessary or when alternative solutions could be found which would be less intrusive. The way that staff deal with incontinence problems may also be experienced by residents as belittling or demeaning. This might involve talking loudly about what has happened, making a fuss about changing sheets, blaming the person or not being discreet about the use of continence aids.

In some long-term care establishments and day care centres mini-buses are used which have the name of the establishment, day care centre or Alzheimer association painted on the side. Some people with dementia may find this humiliating and feel that their privacy is not being respected whereas others may not be fazed, considering that dementia is a condition like any other and nothing to be ashamed of. Some might not even pay attention to this detail. There are arguments for and against this practice. One argument is that it is stigmatising in that it serves as a means to label people on the basis of having dementia. Another argument is that whilst dementia may be commonly considered as a stigma, bringing it out into the open serves to break the taboo and associated fear which contributes towards stigma and it is therefore a positive action against stigma. Both arguments are defensible and opinions on this issue are likely to differ. Unfortunately, the people with dementia who are transported in such vehicles may not all share the same opinion. Some may suffer from feelings of shame and not have the luxury of choosing an alternative form of transport.

Deference patterns and assaults on the self

Goffman (1961) describes a situation in which self-protective expressive responses to humiliating demands (such as expressions of irony, contempt or derision, swearing or sullenness), instead of serving to maintain the person's sense of dignity and conception of self, are turned back on them and lead to further humiliation. This prevents the person from creating a distance from what is happening and to "save face". This extreme control of personal expression is probably not very common in long-term care institutions. However, people with dementia may express themselves in different ways, through subtle and less subtle gestures and actions, especially when they have difficulty communicating verbally. The result may be similar in that they may be categorised as disruptive or as displaying challenging behaviour and thus further controlled in their freedom of expression.

This has similarities to another of Goffman's concepts, namely "assaults upon the self". This concerns the importance of being listened to which involves being seen as capable of receiving and conveying a message about one's actions, sustaining some vestige of the notion that one is self-determining and retaining physical distance from others. The example is given of a person with a mental disorder whose speech is discounted as a mere symptom. This may be accompanied by a rhetorical use of language such as "have you washed today" or "have you got both socks on?" which is accompanied by simultaneous searching (e.g. checking if the towel is wet or looking at the person's feet). This makes the verbal question superfluous and indicates that the interlocutor either does not value or has no interest in the response. Similarly, instead of being asked to do something, a person may be pushed along or have something done to them. Such practices are demeaning and could also be perceived as objectification, infantilisation and acts of coercion. The practice of asking questions to which an answer is not expected or taken into consideration may, on the other hand, reflect a genuine desire to communicate with a person who is not considered able to do so. The extent to which such practices are demeaning may therefore depend on whether the carer has correctly assessed the level of communication and understanding of the person with dementia, and the way in which they interact with the person with dementia.

Freedom of expression and choice

Clothing

In some institutions it is the policy that residents all wear standard clothing which is shared. Sometimes they are given clothes which are not theirs (either deliberately based on the policy of the institution or due to insufficient care and mixing people's clothes up). Clothes are usually chosen for their ease of maintenance rather than style. In some nursing homes, residents are heavily dependent on the home for appropriate clothes which in some cases are obtained from charities. In the UK, collective clothing regimes are not permitted so residents have to wear their own clothes. However, according to Twigg (2010), standardised forms of clothing provided by the state and shared by residents are still common in some countries such as Finland (Topo and Iltanen-Tähkävuori, 2010). This practice may diminish personal identity and self-esteem. It devalues, dehumanises and is disrespectful. In addition, it fails to respect autonomy and the possibility

for residents to express themselves (i.e. their personality, style, mood and social status). Moreover, it undermines the importance of supporting the identity and personhood of people living with dementia.

Depriving people of the freedom of expression through vestimentary choice is sometimes due to greater importance being given to the convenience of care staff. Sometimes, it reflects rules about washing which do not extend to wool or delicate fibres. There may be regulations, especially in the case of incontinence, that clothing be washed at 65°C for 10 minutes which rules out certain fabrics (Twigg, 2010). Personal belongings such as clothes may therefore interfere with the smooth running of the institution as staff have to keep track of people's clothes and wash them separately. Ensuring that residents share the same clothes also saves time (linked to choice) and means that staff can make choices based on efficiency rather than on residents' autonomy, self-esteem and personal identity (Goffman, 1961). In this way, people with dementia in care homes often have to adapt to the rules and in so doing lose some of their freedom of expression and choice.

People express their personality, mood and style through clothing. It can also be used as a means to convey social class. Depriving someone of the freedom/right to wear what they choose may prevent such self-expression. Drawing on Hughes' concept of the situated embodied agent whereby a person physically acts in a specific culture and historical and social context, Twigg (2010) argues that clothes are part of this and of the continuing narrative of self through which people express their position within particular social worlds. The clothes that people in some establishments end up wearing may be totally inappropriate to their style and habits. It has been argued that people with dementia lose interest in dress and appearance, and later in personal hygiene (Jenkins and Price, 1996). Kontos (2004) showed in an ethnographic study that this is probably not the case, providing examples of people with advanced dementia carrying out habitual gestures of grooming such as trying to put on lipstick whilst approaching a social event and placing a pearl necklace in front of a bib.

Twigg (2010) argues that people with dementia are often given clothes which are "comfortable" and easy to get on and off but that people with dementia do not all have the same notion of comfort and may feel very uncomfortable or uneasy sitting around in what they feel are inappropriate clothes such as track suit trousers and T-shirts. She adds that for men, trousers without a zip fastener may be perceived as a challenge to their masculine identity and a form of infantilisation. This demonstrates that psychological comfort as well as physical comfort may be equally if not more important. Calnan et al. (2006) point out that older people (without dementia) regard dress/attire as a significant aspect of dignity and that being properly dressed when not able to dress oneself is a sign that one is being treated with respect.

Personal belongings

Personal items and clothing often go missing in institutions. Perhaps they are stolen, perhaps they are mislaid or given away. Losing personal items can be distressing for any-

one, especially if they have sentimental value. For people who are living in institutions, personal items may enhance their feeling of autonomy and security (MDAC, 2011). Some of the items may be nostalgic and emotionally laden (e.g. photos of a deceased spouse, grandchildren who never visit or a pet which had to be rehomed). It might not be possible to ever replace them. The loss may serve as an irreparable loss of a visual reminder of the past. The loss of possessions can also be disturbing to relatives and carers who may have bought them for the person with dementia and may also be upset at seeing that person wearing inappropriate clothes which are not their own.

People with dementia who live in institutions have the same right as anyone else to own personal possessions and for those personal possessions to be properly protected yet in some homes, there are no lockable cupboards or rooms. In any other situation, the loss of a personal item would be taken seriously and attempts made to recover it. Legal steps might even be taken. With dementia, the person taking the item might not be aware that it is not theirs but it cannot be presumed that this is always the case. Moreover, items may be taken by staff or visitors. There may be a tendency to underestimate the importance of items which go missing in institutions or to consider this as inevitable and, in so doing, fail to prevent harm arising from that loss.

The provision of locked cupboards may occasionally lead to problems with the hoarding of food which is then eaten when rancid, as well as the loss of keys. Whilst these problems would need to be addressed, they should not be considered as grounds to prevent people with dementia from having lockable cupboards.

Residents often have no control over finances or their access to money is limited. This also applies to many people with dementia living at home with relatives or who have a legal guardian with responsibility for finances. Those living in institutions may, in addition, lack the opportunity to buy clothes or personal items (MDAC, 2011). They have little opportunity to go shopping and the wisdom of certain purchases may be challenged on the grounds that they are not useful or necessary. Frivolous purchases may be perceived as evidence of vulnerable people being taken advantage of. In some institutions, residents might be able to purchase items and services through catalogues and "Tupperware style" events or services such as a manicure or haircut (if the providers visit establishments). The freedom to be a consumer may also be limited for people living at home who cannot go out shopping alone and are not taken out. Shopping is not merely functional. It is about having the power to purchase, the opportunity to go out, see different things, meet people and chat and a way to express individuality and choice.

Twigg (2010) highlights the symbolic transition towards death starting with the gradual loss of possessions (e.g. things get stolen, no place to put possessions, staff think they are not necessary etc.) to the ultimate loss of all possessions through death. Within this process, the loss of objects with sentimental value or which are nostalgic may further erode memories and the link a person has to their own past.

Personalisation of living area

The right to have personal belongings has been discussed in terms of the right to express oneself and be surrounded by familiar objects. People who live in institutions are usually deprived of the right to make decisions about the environment in which they live, both the communal living areas such as lounges and kitchens and the private living areas such as bedrooms and in some cases bathrooms. Day after day, residents sit in chairs, sleep in beds, eat at tables and look at an interior design which they did not choose. Irrespective of whether they like these objects and the overall design, the fact that they are not consulted represents a lack of respect for their autonomy or concern for their well-being.

Opportunities for privacy, including the possibility to personalise living spaces in residential care settings, were found to reduce agitation in a study carried out in America (Zeisel et al., 2003). The possible effects on behavioural disorders of the personalisation of living spaces for people with AD were tested in four special care units in a hospital in France (Charras et al., 2010). In two of the units, residents and families were encouraged to personalise rooms with the help of a member of staff but not in the other two units which served as a control. Personalisation was not found to reduce agitation but it was associated with a tendency to gain weight (which the researchers interpret as a measure of quality of life), less disinhibition and less apathy. The researchers suggest that the personalisation of rooms might serve a similar function to reminiscence work, by stimulating memory and other cognitive and affective functions, as well as enabling professional carers to become better acquainted with each resident. The freedom to personalise living areas therefore has implications for health, well-being and quality of life.

In group living situations, decisions about furniture and furnishings may be affected by a range of factors such as cost, maintenance and safety but even within these constraints, it would be possible to involve people with dementia when new purchases or changes are made. If some people with dementia are unable to communicate their preferences, carers may be able to help as they are likely to know the fabrics, colours and styles they prefer. As with any group, there would be different preferences and tastes amongst the residents. Residents should nevertheless be consulted about decisions concerning the environment in which they live 24 hours a day. This was shown to be possible in a study carried out in eight special care units in France involving 63 people with dementia (Charras et al., 2011a). In this study, after a two-day period of observation of how residents, staff and relatives used the space, related to it, moved around and interacted, a series of arrangements for the environmental design were proposed by the researchers. Financial constraints, security issues, technical feasibility and the remarks made by all concerned had all been taken into account. The residents were further involved in the implementation of the proposed changes through participation in the choice of furniture, materials and colours. Various methods were used to achieve this such as catalogues, examining different possibilities, going together to specialised stores and asking representatives of stores to come to the special care unit.

Non-individualised care

Many residents live, eat, wash, socialise, dress, undress and sleep in the same room as other people (MDAC, 2011). This represents a total lack of privacy and a failure to respect individuality and choice. It also deprives people of the freedom to totally relax, be themselves, collect their thoughts and “switch off”.

In many residential care settings, care staff have working routines which help them organise their work and ensure that everyone is provided with the care, services or support they need. The issue of justice is relevant as care staff have to ensure that they care for everybody and do not spend a disproportionate amount of time attending to the needs of a small group of people. However, this means that residents often have to fit into the schedules of care staff and not vice versa. Another consequence is that care may be provided at times which are inappropriate or undesirable (e.g. people may be wakened at 6 o'clock in the morning to be washed, have to wait until 10 o'clock for breakfast or be helped into bed at 8 o'clock in the evening). It also means that some people will be hungry and have to wait for a meal whereas others will be offered food when they are not hungry.

Assistance with washing (and bathing) is also often provided in a way which does not respect the needs and wishes of the individual. According to Gastmans (2004), washing (and bathing) has become a routine, taken-for-granted ritual and symbol of good care. However, he suggests that washing is more than a physical action and has ethical implications. He highlights the need to respect people's privacy and dignity, their intimate sphere and their bodily integrity, to take into consideration their preferences about the manner in which they are washed and what they have become accustomed to in their lives and to be attentive to their needs in order to promote their well-being. Gastmans (2004) points out that time constraints may result in failure to respect people's rhythm and rule out the possibility for them to participate in the task or to wash themselves (which may reduce their opportunity to express their autonomy). Gastmans (2004) emphasises that residents are not passive recipients of washing and that failure to ensure that the manner in which they are washed or bathed corresponds to their needs may result in shame, loss of self-esteem and identity, fear and aggression. This is not in keeping with respecting personhood, promoting well-being and the principles of beneficence and non-maleficence. These same issues would equally apply to people with dementia in need of assistance with washing at home.

According to Sloane et al. (1995), coercion should only be used to ensure that a person is washed if failing to do so would lead to serious health problems. It is probably quite rare that not washing would lead to serious health problems or that coercion could be justified. There is a risk that coercion might be too hastily applied without the necessary care and attention having been given to discovering possible reasons for the person's refusal which they may be unable to communicate and which may be linked to their past, the way that washing is carried out, the environment or other physical, practical or emotional factors.

In some institutions, some services are offered on the basis of quite rigid “rounds”. This is often the case for tea (or coffee depending on the traditions of each country) which is provided at certain times of the day. Drinking, like breathing in air, is a physical necessity and should not be restricted under any circumstances. Whilst this need could be satisfied with water which might be readily available, people with dementia may forget to drink or not be accustomed to drinking water. Tea rounds are a good way to remind residents at regular intervals to have a drink and avoid dehydration. Having a cup of tea can also be a social act. It can bring people together and provide an opportunity for small talk and interaction. Being able to offer visitors a warm drink is also a social convention, which gives people with dementia an opportunity to demonstrate hospitality and to reciprocate, which according to (Vernooij-Dassen et al., 2011) is often lacking. People also drink tea and coffee out of boredom or habit, in order to relax or for the pleasure of the taste. It is therefore important that tea is not provided solely on a functional, routine basis which does not respect their autonomy or individuality, or promote their well-being.

Another example of care provision which is not adapted to individual need is the “toilet round”. In some establishments, residents who need assistance to go to the toilet are obliged to wait until set times at which they may be accompanied by care staff. Artificial and external control of this basic human need may lead to discomfort, stress and problems with continence. Some residents may have visitors who can accompany them to the toilet at other times and some may have the means to pay for additional assistance. However, not all have such opportunities and this creates a system of discrimination and inequity in the provision of care. This system of toilet rounds may also contribute towards the inappropriate use of continence aids such as continence pads, commodes and catheters. People may be designated as having continence problems simply because they cannot adapt to the system of care provided. Such measures therefore restrict the freedom to go to the toilet if and when necessary. They may also result in shame and reduced mobility. Continence aids may be necessary and appropriate for some people with dementia depending on their needs but their inappropriate use is abusive and unethical.

With regard to choice of food, it might be unrealistic to expect establishments to provide residents with the possibility to choose from a varied menu. Dietary requirements linked to religious beliefs, food intolerances and life choices (such as being a vegetarian) should nevertheless be respected. However, people may also have strong dislikes and preferences. Food may be one of the pleasures in life they can still enjoy and this should be taken into account. The timing of meals, the quantities provided at each meal and variety in the meals provided may be important to residents’ well-being and are areas where feedback could be sought. Even small changes to standard procedures could have an impact on well-being and respect the autonomy of the residents. While the principle of justice is relevant to ensuring that a system is in place which means the needs of one group do not lead to the neglect of another, it is also important to understand that treating different situations the same is not just or equal. Rules and practices which are applied equally to everyone may have a disproportionate adverse impact on people with dementia or other disabilities and thus constitute a form of indirect discrimination.

Spirituality and religious beliefs

People with dementia may have spiritual and religious beliefs or practices which are meaningful to them. These should be respected and, as far as possible, fostered.

As institutions may have residents practicing a range of religions, it may be difficult to provide places of worship for each religion. In some establishments, including hospitals, there are common places of worship where people from any faith can gather. Setting up such a room does not require a huge investment and may be particularly welcomed by residents who are not able to attend public services in the community. Religious leaders could be invited to visit and hold services. However, according to the principle of reasonable accommodation, efforts should also be made to enable people with dementia to attend public services. This would enable them to participate in society on an equal basis with other members of the community. If establishments do not have the means to provide transport and staff, it may be possible to involve members of religious communities or volunteers to accompany people with dementia.

It is also important to respect the right not to practice religion. In countries where care institutions are often run by religious orders or have a religious ethos, people of minority religions or no religion, or who have ceased to believe in or practice the religion they were brought up in, may find themselves in religious environments through lack of genuine alternatives. They may find themselves being included in religious ceremonies (often through an assumption that they will wish to be included rather an intention to coerce), visited by clergy, or in an environment where there is a lot of religious iconography. It is important also to remember that some people may have had a profoundly negative experience of religious institutions (for example the prevalence of physical and sexual abuse in religious-run schools and children's homes in Ireland is well documented)⁸. In these cases, environmental factors which are comforting to many and may seem innocuous may in fact trigger feelings of disempowerment or in some cases extreme distress. It is essential that staff are aware of the subtler environmental factors relating to the practice or non-practice of religion and proactive and sensitive about establishing an individual's preferences rather than simply making assumptions based on the demographic to which the person belongs.

With regard to spirituality, this is sometimes more difficult to grasp. According to Holloy and Seicol,

"Spirituality is not what many think it is. Spirituality is to do with who we are and what life is about. It is not far away. It is very close to where we live. It has to do with our deepest longings, our sadness and joy, our loneliness and friendships, our fears and our times of trust, our beliefs and our disbeliefs. It has to do with the very essence of our being" (cited in Bell and Troxel, 2001).

⁸ For more details, see: <http://www.childabusecommission.ie/>

As such, it could also be understood as covering the major existential themes described by Yalom (1980) i.e. death, freedom/responsibility, isolation/loneliness and meaninglessness. Spirituality is therefore a broader term than religion. Whilst many people express their spirituality through religious practice, others express it through their relationship with nature, music, the arts, family and friends or a set of philosophical beliefs (Sulmasy, 2002). In fact, there is a risk that healthcare professionals who equate spiritual needs with religious needs might overlook the spiritual needs of people who do not overtly practice a particular religion (Narayanasamy et al., 2004). Spiritual and religious beliefs and practices may be shared or private but they are very closely linked to individuality which people with dementia should be free to express and which should be respected by others.

Control through procedures and environmental factors

Charras et al. (2011b) draw attention to the way that residents in institutions are sometimes manipulated into taking certain choices or behaving in ways which restrict their freedom of movement. An example is the dimming of lights in certain areas at certain times of the day to dissuade people from going there. Another example is the practice of locking doors to people's rooms during the day in order to force them to occupy the communal areas and prevent "wandering". The authors suggest that most toing and froing between private and communal areas is not without purpose but rather part of claiming the living area as a real home and of marking the difference between "my home" and "our home". However, this is unlikely to occur if care staff are over-protective and restrict the rights of residents to make use of facilities (e.g. by barring access or requiring authorisation to use the kitchen). In such cases, the atmosphere and freedom that is typical of real homes (with real kitchens where people can go and make a cup of tea or a snack) would be a simple façade and a reminder of the freedom that the residents have lost. Moreover, as pointed out by Merton (1968), preventing people from carrying out certain tasks due to the possible dangers involved may serve as a self-fulfilling prophesy resulting in the loss of the skill which then may result in a potential danger. Nevertheless, official health and safety regulations would have to be adhered to within care homes in order to avoid litigation in case of accidents. On the other hand, the use of assistive technology, perhaps including surveillance technology, might help ensure that regulations are respected.

Monotony and denial of opportunity

The restriction of opportunities and of the right to choose may lead to a monotonous existence. Restrictions might include access to leisure and social activities, access to fresh air and the absence of daily activities and pleasures (including smoking, drinking coffee or alcohol and having a nap). In some establishments, staff control access to cigarettes and the right to smoke. Whilst there may be medical reasons which indicate that smoking is not in a person's best interests, it must be acknowledged that it is not in anyone's best interests to smoke and yet most people retain the right to do so. It is unlikely that a person with dementia would have taken up smoking after the onset of dementia, having never smoked before. Consequently, it would be unjust to deprive them of the right to smoke based on having dementia. Increasingly, buildings are becoming non-smoking and residents may have to go to certain areas to smoke. This is the same for everybody in

public buildings but for people in residential care, it is their home. If they need assistance to go to the place where smoking is permitted, they may be dependent on the goodwill or availability of staff who may prefer to take several people at the same time. This takes away the freedom of smoking as a spontaneous act, a pleasure or a response to a need. If a person is unable to go outside and the building has become their whole living area, the need or desire to smoke may go unmet. If they have the capacity to decide to go into a residential home which has a no-smoking policy, this would not be unethical provided that they knew in advance and had a real choice in accepting to live there.

Other issues, linked to a monotonous existence and lack of opportunities, include the practice of leaving residents sitting in a chair all day long and all evening. If meals are provided, shopping is taken care of, rooms are cleaned and maintenance of a car, garden or house front not possible, there is no opportunity or need to do anything around the "home". People may appreciate this for a couple of days, but few would probably like an existence consisting solely of this. Yet this is what happens in some homes. People have nothing to do and are therefore also limited in what they can talk about with the same people they see every day. Lack of stimulation, movement and objectives may contribute to social withdrawal and apathy in a kind of self-fulfilling prophesy. Social activities and stimulation should be considered a part of good care and not a luxury or the responsibility of families and friends. People with dementia who move into residential care may still appreciate going to a pub, supermarket or flea market, watching a rugby match or flower arranging. Such activities may take some organisation and pose logistical challenges but these are not insurmountable as demonstrated by homes which do provide such activities. Activities and social and cognitive stimulation should nevertheless be geared towards the interests of the residents which must first be ascertained.

2.3.3 Sexuality and relationships

This section addresses issues related to relationships between and involving people with dementia and the issue of sexuality. Relationships may be based on blood, marriage, kinship, friendship or emotional, psychological and sexual connections between people. Our emphasis is on the emotional, psychological and sexual aspects of relationships. Sexuality has been defined in a number of ways. Our definition covers sex (in terms of sexual activity, not just sexual intercourse), gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and, in the case of younger people with dementia, reproduction.

According to the World Association for Sexual Health (1999), sexual rights are fundamental and universal human rights "based on the inherent freedom, dignity, and equality of all human beings". They further state that sexual rights must be recognised, promoted, respected, and defended by all societies through all means. Sexuality is further described as being dependent on the satisfaction of basic human needs such as contact, intimacy, emotional expression, pleasure, tenderness and love. It may involve a combination of biological and psychological or emotional influences and can also be influenced by cultural, legal, historical, social, economic, political, religious and spiritual factors. The following declaration outlines a number of sexual rights which also have implications

for relationships. They are therefore useful to bear in mind when considering an ethical approach to sexuality and relationships with regard to people with dementia.

World Association for Sexual Health: Declaration of Sexual Rights

1. **The right to sexual freedom.** Sexual freedom encompasses the possibility for individuals to express their full sexual potential. However, this excludes all forms of sexual coercion, exploitation and abuse at any time and situations in life.
2. **The right to sexual autonomy, sexual integrity, and safety of the sexual body.** This right involves the ability to make autonomous decisions about one's sexual life within a context of one's own personal and social ethics. It also encompasses control and enjoyment of our own bodies free from torture, mutilation and violence of any sort.
3. **The right to sexual privacy.** This involves the right for individual decisions and behaviours about intimacy as long as they do not intrude on the sexual rights of others.
4. **The right to sexual equity.** This refers to freedom from all forms of discrimination regardless of sex, gender, sexual orientation, age, race, social class, religion, or physical and emotional disability.
5. **The right to sexual pleasure.** Sexual pleasure, including autoeroticism, is a source of physical, psychological, intellectual and spiritual well-being.
6. **The right to emotional sexual expression.** Sexual expression is more than erotic pleasure or sexual acts. Individuals have a right to express their sexuality through communication, touch, emotional expression and love.
7. **The right to sexually associate freely.** This means the possibility to marry or not, to divorce, and to establish other types of responsible sexual associations.
8. **The right to make free and responsible reproductive choices.** This encompasses the right to decide whether or not to have children, the number and spacing of children, and the right to full access to the means of fertility regulation.
9. **The right to sexual information based upon scientific inquiry.** This right implies that sexual information should be generated through the process of unencumbered and yet scientifically ethical inquiry, and disseminated in appropriate ways at all societal levels.
10. **The right to comprehensive sexuality education.** This is a lifelong process from birth throughout the life cycle and should involve all social institutions.
11. **The right to sexual health care.** Sexual health care should be available for prevention and treatment of all sexual concerns, problems and disorders.

Adopted in Hong Kong at the 14th World Congress of Sexology, August 26, 1999

All of these recommendations could be applied to people with dementia although two recommendations are more limited in their applicability. Recommendation no.7, for

example, addresses an issue which may be affected by guardianship measures in some countries. However, it is nevertheless valid in terms of this right not being denied solely on the grounds that a person has dementia. Recommendation no.8 is clearly targeted at people of reproductive age or capacity but would be applicable to younger women with dementia of child-bearing age and to men with dementia in terms of sharing responsibility for contraception when in relationships with younger women.

In the remainder of this section, we will look at what is already known from the literature about attitudes and practices with regard to the sexuality and relationships of people with dementia. This will be followed by a discussion about the relevant ethical issues.

Practices and attitudes towards sexuality and relationships

Taboo, stereotypes and stigma

Sex amongst older people is often considered taboo and stereotypes exist about older people and sex. Negative attitudes towards the sexuality of people with disabilities and mental disorders are also common. Bamford (2011) suggest that older people with dementia face the “double jeopardy” of being old and cognitively impaired. Consequently, sexual behaviour by older people, especially those who have dementia, is sometimes considered as pathological (i.e. involving, caused by, or linked to a physical or mental disease) and not a natural, healthy activity or interest. As people with Down’s syndrome tend to develop Alzheimer’s disease at a younger age, they may be labelled as having a disability. People with disabilities are also often inaccurately considered as being asexual beings (Milligan and Neufeldt, 2001). Older people, people with dementia and people with disabilities all risk being stereotyped as asexual.

Stereotypes and myths about older people and sexuality are not only common amongst the general public but also in the healthcare domain (Benbow and Beeston, 2012), especially with regard to institutionalized older people (Glass et al., 1986). Older people are considered unattractive, uninterested in sex and sexually inactive (Mahieu, Van Elssen and Gastmans, 2011; Tabak and Shemesh-Kigli, 2006) but their own perceptions of the importance of sex vary. A qualitative study which involved indepth interviews with 21 men and 23 women aged between 50 and 92 had mixed findings. It was found, for example, that people who had no partner and did not expect to have one in the future placed no importance on sex, whereas those who did have a partner all attributed some importance to sex, many stating that it was very or extremely important (Gott and Hinchliff, 2003). However, it has been suggested that older people may collude in the stereotype of asexuality by passing as asexual and keeping their interest in and expression of sexuality secret (Nay, McAuliffe and Bauer, 2007). As stereotypes are based on the norms and values of society (Goffman, 1963) and represent a key component of stigma (Link and Phelan 2001; 2006) and as stigma serves to maintain power relations within society (Parker and Aggleton, 2003), a person who breaches social stereotypes risks being considered as deviant and being sanctioned. The expression of sexuality amongst older people and people with dementia is frequently discussed in terms of a problem or deviation from the norm.

Sexuality, morality and social norms

Sexuality is a topic which is sometimes associated with religious beliefs and cultural norms which result in some practices being considered immoral, anti-social, shameful or offensive to others. Most cultures have unspoken rules and about which types and to what extent sexuality can be publicly exhibited, and in some cases only between certain categories of people. There are also contractual issues such as marriage and in some countries prostitution to be considered. A person's religious or moral beliefs may mean that they consider sexual relationships between unmarried people, access to pornographic materials, extramarital sex or sex that this not for the purpose of procreation unacceptable, regardless of the mental capacity of the people concerned (Perlin, 1994). On the other hand, issues related to the sexuality or relationships may be considered differently if they involve people with dementia, perhaps resulting in greater tolerance (due to lack of perceived responsibility) or, on the contrary, in the desire to exert more control (e.g. in order to maintain respectability) (Archibold, 2002).

Sexuality and relationships within the LGBT community

Nowadays, people with dementia from the LGBT (lesbian, gay, bisexual and transgender) community are hopefully offered the same services and care opportunities as heterosexual or asexual people with dementia. However, there may sometimes be subtle forms of discrimination against them using these services and the services may not always be suited to their needs and wishes. Moreover, the LGBT community is not a homogenous group.

“Older LGBT people are not all the same, there are generational differences within this diverse group. Those who grew up pre gay liberation have endured a lifetime of having been vilified as ‘sinners’ by the church, ‘criminals’ in law, and pathologised by medicine. Consequently, this group experiences ageing differently and has distinct needs compared to the baby boomer cohort which is now approaching retirement. (.../...) For many, getting older means an increased fear of being “outed” after a lifetime of avoiding disclosure, or a fear of being sent back into the closet to avoid facing discrimination at a particularly vulnerable time in their lives.” (LGBT Health website, Australia, 2012)

An extensive literature review and study into the lives of older LGBT people in Ireland provides insight into many issues of relevance to older LGBT people with dementia. Examples include the fear of their LGBT identity and key partners not being recognised or respected, discrimination and being dependent on services provided by religious-based organisations (Higgins et al., 2011).

The freedom of older people from the LGBT community to decide whether or not to disclose their sexual identity may be threatened when they move into residential care. They may find themselves reluctantly “coming out” for the first time or yet again (Bamford, 2011). This may also be the case for those who continue to live in their own homes but require home care although this is less public. Bamford (2011) reports that many people from the LGBT community choose not to go into residential care, even at great personal cost, or assume heterosexual behaviour within care homes due to the fear associated

with disclosure of their sexual identity. Such fears may sometimes be well founded. In some cases, staff, other residents, home care workers, family and acquaintances may be prejudiced, embarrassed or ignorant about LGBT relationships. This represents a triple jeopardy of being discriminated against or devalued based on being old, cognitively impaired and from the LGBT community.

It is important to respect people's privacy, individuality and sexual identity, bearing in mind their past history of relationships. However, Bamford (2011) points out that this may sometimes be misleading. Some people may have hidden or repressed their homosexual tendencies for all or parts of their lives but their social control may weaken as a result of dementia, thus resulting in the expression of a different sexuality. Others may reassess what is important to them at that stage of their lives and consciously decide to "come out". This raises the issue of personhood and which is the "true self". Relatives may have difficulty accepting the current choices or lifestyle of the person with dementia even if the latter is clearly happy. The current sexual identity may be perceived as "wrong" based on their knowledge and understanding of the person's history, preferences and values. Carers and relatives may fear that the person is being exploited or feel the need to protect their social dignity. They may also simply have difficulty coming to terms with a different image of the person with dementia based on their own prejudice or relationship to them.

The knowledge and attitudes of professional carers

A review of 30 studies into nurses' perceptions of sexuality in older people in residential care revealed the importance of their knowledge about sexuality of older people and their attitudes towards such sexuality amongst their residents (Mahieu, van Elssen and Gastmans, 2011). Overall attitudes were quite positive although less so with regard to erotic behaviour which tended to arouse feelings of shame and discomfort. There was also evidence of some degree of stereotyping about older people being incapable of leading a fulfilling sexual life. Most of the studies which had used quantitative methods reported positive attitudes and these were significantly correlated to educational level. Studies which had used qualitative methods (e.g. based on interviews or focus groups) did not report such positive attitudes. Mahieu et al. (2011) suggest that this may be partly due to the different methodologies and underlying paradigms which make comparison difficult. They also highlight studies which suggest that staff with a higher level of education have more permissive sexual attitudes.

Place of residence

Many issues linked to the sexuality and relationships of people with dementia apply in the context of people's own homes as well as in residential or semi-residential care. However, in the formal care setting, it is possible that these issues take on a different significance as people do not have the privacy of their own home, they may have been distanced from existing relationships (which may or may not have been positive), they are expected to comply with the rules of the establishment and may be exposed to the interfering social and moral judgements of other people. At the same time, they are more or less obliged to spend the rest of their lives with other people, with whom they did not choose to live,

but to whom they may become sentimentally attached and sexually attracted (Kuhn, 2002). Some situations may therefore arise in the formal care setting and be perceived as dilemmas which would not occur or be considered problematic in the private setting. Others (e.g. involving solitary activities, sexually inappropriate behaviour or advances towards outsiders), especially behaviour which seems to be “out of character” may be perceived as problematic wherever it occurs. It may also be the case that a sexual habit which was never a problem at home (such as cross dressing or paying for the services of an escort or paid sex worker in countries where this is legal) is not tolerated in long-term residential care homes.

Changes in relationships

Changes in relationships, in which one person has dementia, have been explored and found to be mainly negative but with some positive experiences. For example, a sample of 47 married partners of people with dementia in the UK completed an adapted version of the Marital Intimacy Scale which revealed that 22.5% of the couples were still having a sexual relationship and all were satisfied with it (Ballard et al., 1997). The remainder were no longer having a sexual relationship but 61.3% of those were happy with the situation, compared to 38.7% who were not. Amongst those who were dissatisfied with having no relationship, a significantly higher proportion were linked to a partner with vascular dementia who tended to be younger. Unfortunately, no further details were provided about the quality of the relationship.

However, another more recent study, explored both the sexual and the non-sexual nature of relationships by means of focus group discussions. 16 people with early stage dementia and their partners (aged between 56 and 77) revealed their concerns about role loss, dependency, role reversal (e.g. the relationship starting to resemble a parent/child relationship) and finding the right balance and respect despite changes in power relations (Braudy Harris, 2009). Positive perceptions of the impact of dementia on relationships included personal growth and the reconfirmation of the couple’s marital commitment. With regard to sexuality and intimacy, perceptions were varied. A few couples felt that dementia had not had any impact on their intimate relationship and some described their relationship as having become more platonic but deeper. They felt that they had less physical, sexual contact but that they had grown closer and become more intimate at other levels. Some felt that they had limited feelings of intimacy and were less satisfied with their sexual relationship. This was associated with frustration, anger and disappointment.

The above studies should not be considered as representative of the relationships of all people with dementia, especially as they only relate to heterosexual, marital relationships. However, they show how one partner having dementia can affect relationships in different ways and that the sexual and non-sexual sides of the relationship are equally important to consider.

Within the context of residential care, staff are usually encouraged to have a professional relationship towards residents but this does not mean being cold and detached. Varying

degrees of friendship and caring may develop. Sometimes, tasks involving intimate care can be misinterpreted or evoke comments or actions which are not in keeping with the professional nature of the act. This can be difficult to manage and staff do not always receive appropriate support from fellow staff or management (Archibold, 2002).

2.3.3.1 Ethical issues linked to sexuality and relationships

A number of ethical issues were addressed in a review of the literature on this topic carried out by Mahieu and Gastmans (2012). The review covers 25 articles published in the last 30 years in English, French, German or Dutch. Mahieu and Gastmans (2012) detected an imbalance in the literature with greater attention being paid to the bioethical principles of Beauchamp and Childress (namely, respect for autonomy, beneficence, non-maleficence and justice) at the expense of care-based ethical arguments. Moreover, the authors conclude that “there is a pressing need for a better defined, more fundamental philosophical-ethical analysis of the values at stake” (p.346). They propose a broader ethical framework to address sexuality amongst older people which is equally applicable to people with dementia. In addition to the bioethical principles, their framework includes ethical care-orientated arguments reflecting care, dignity, vulnerability, singularity, historicity and relationality. In the context of residential care, they also highlight the need to address sexuality at three levels:

- The individual level: how to deal with the sexual behaviour of the resident.
- The relational level: how staff should deal with the sexuality of the resident (question of attitudes)
- The institutional level: how should the institution create an atmosphere in which sexuality can be addressed.

With biomedical ethics, respect for autonomy is a predominating factor. It is often considered that if people are able to consent, their freedom must be respected but many people with dementia lack this ability. Also, there are different issues at stake with regard to a proposed treatment compared to having an emotional, sexual or platonic relationship with somebody. The desire for companionship, intimacy, love and meaning to life cannot be evaluated in the same way as consent to medical treatment. It is therefore problematic to transpose the biomedical paradigm onto a completely unrelated issue. Trying to do so, leads to the medicalization of daily life but sexuality and relationships are not medical problems. Unfortunately, the care approach is not well developed.

In the following sections, issues related to the various bioethical and care principles are discussed and some of the associated ethical issues raised.

Respect for autonomy

Informed consent

The principle of respect for autonomy covers the right to decide for oneself about relationships and sexuality. Private sexual relations between adults rarely involve a contractual, signed agreement but are always considered as necessitating the consent of both

parties and the condition that neither was coerced. Otherwise, it would be considered as rape or abuse.

The capacity to consent is task specific. People do not have an overall capacity to consent covering everything from driving cars, making a will and undergoing surgery to having a relationship. However, there is a risk of underestimating the capacity of people with dementia to have sexual relationships if presumptions are made about their capacity based on their capacities in other areas of life. As Kuhn (2002) points out, "A resident may perform poorly on a mental status test but his or her preference for a special friend or lover may be quite evident" (p.167), adding that attempting to determine an "all or nothing" global competence is not likely to be a useful approach. Surely, evidence that a person with dementia has formed an affective tie to another person should not be ignored when considering the issue of consent to a relationship with that person, even if affective ties are not considered a necessary criterion to engage in such relationships.

In most countries, there is a presumption that a person has capacity unless it has been proven otherwise and consequently, there are criteria or guidelines in specific domains to determine whether a person has such capacity. With relationships, the situation is perhaps somewhat different. People do not always make an initial or calculated decision to start a relationship or friendship. Moreover, it could be argued that becoming emotionally attached to someone does not require a particular capacity. On the other hand, people with dementia may be vulnerable to financial or other abuse in the context of relationships.

Lichtenberg and Stzeppek (1990) proposed a set of guidelines to assess whether people with dementia living in residential care settings should be allowed to engage in sexual relationships. The authors emphasise the potential benefits of sexual activity and state that informed consent is generally understood to require three conditions, namely voluntary participation, mental competence and awareness of the risks and benefits. Their guidelines, address three issues which are not quite the same, namely awareness of the relationship, the ability to avoid exploitation and awareness of potential risks.

Awareness of the relationship involves awareness of who is initiating the sexual contact and the absence of any delusions or mistaken identity (e.g. mistaking the other person for their spouse or partner) but also having the ability to state what level of sexual intimacy they would be comfortable with.

The ability to avoid exploitation focuses on two factors. The first is whether behaviour is consistent with formerly held beliefs and values. This raises questions about the perceived authenticity of personhood of people with dementia which will be addressed below. The second factor is whether the person with dementia has the capacity to say no to any unwelcome sexual contact.

The awareness of potential risks is assessed on the basis of the person's realisation that the relationship may be limited in time and whether they can describe how they would

react when the relationship ends. This is based on the fact that the study was set in a temporary unit and is not very helpful to other settings.

These factors are perhaps useful to consider but overemphasise negative issues. They do not give equal importance to the potential benefits of possible sexual relationships. Also, they require consistency with past behaviour and values which may nevertheless change. The assessment of the person's ability to say "no" does not take sufficient account of the kind of subtle psychological coercion which might be exerted on people with dementia either by staff, residents or other people. People with dementia may be particularly vulnerable to sexual abuse if they are dependent on the people caring for them and due to the unequal power relations between staff and residents in nursing homes.

This approach seems to reflect a medicalization of the sexuality of people with dementia. However, Lichtenberg and Strzepek (1990) argue in favour of adopting caring as an ethical approach based on the work of Nel Noddings (1984) who reportedly argued that:

"Caring is based on the receptiveness, relatedness, and responsiveness of the one caring to the one cared for and that in order to truly care, one must give appropriate attention and credit to the affective foundation of existence." (Lichtenberg and Strzepek, 1990, p. 117).

Authenticity of personhood

In the guidelines developed by Lichtenberg and Strzepek (1990), assessment of the ability to avoid exploitation was linked to a consideration of whether the person's behaviour was consistent with formerly held beliefs and values. The issue is not whether a person with dementia can or should change. Rather, it is about the authenticity of personhood. In other words, a person whose behaviour changes to such an extent that it no longer seems to be in keeping with the values and beliefs they formerly held, may seem to have become a different person. Clearly, this is not the case and people change throughout the course of their lives. However, in dementia, the change can sometimes seem so radical that some people make a distinction between the "then" self and the "now" self. This is linked to the importance attached to awareness of one's own past (and to one's values and beliefs which develop throughout one's life) as opposed to "living in the moment".

According to Mahieu and Gastmans (2012), theorists are divided on this issue. Some emphasise the importance of the "then" self, arguing that the values and beliefs held in the past are important, particularly the "critical interests" which made life meaningful as they define the person's identity. Consequently, they should be taken into account when deciding on the appropriateness of current sexual behaviour and not the "experiential interests" linked to living in the moment. If the sexual behaviour is not in keeping with past values and beliefs, it may be considered offensive to that person's own dignity (Berger, 2000). Other theorists, such as Tenenbaum (2009), emphasize the need to balance critical and experiential interests, arguing, nevertheless, that the value of an intimate relationship may be greater than the threat it poses to critical interests. Post (2001), on the other hand, is opposed to the strict bifurcation of the self in the "then" self

and the “now” self. He argues that it is nonsense to claim a radical discontinuity between the past and current selves and that up to the advanced or terminal stages, a person may have moments in which they recollect former relationships and may experience intense shame or guilt about current relationships.

Beneficence

Older people, including those with dementia who still engage in sexual intercourse, have sexual feelings and appreciate intimacy contrary to stereotypes that they are incapable or not interested (Braudy Harris, 2009; Kaplan, 1990; Skoog, 1996). Several studies suggest that sexual activity is proven to have a positive psychological and physical impact on the lives of people living in residential care (Mahieu and Gastmans, 2012). There are therefore sufficient grounds to support beneficence as an ethical argument in favour of promoting rather than opposing sexual activity and relationships involving people with dementia. However, at the individual level, concerns are often expressed as to whether sexual activity or a relationship is completely beneficial and whether the benefits outweigh possible harm. This raises the issue of nonmaleficence which is addressed later.

Intimacy and touch in non-sexual relationships

According to Bouman (2003), the need for human affection, intimacy and touch remains important even for people with advanced dementia who have become less interested in sexual activity. Intimacy and touch may also occur within the context of care and is closely linked to both privacy and beneficence. It may be considered as contributing to a person’s sense of well-being and therefore as beneficial, or perhaps negatively as an intrusion into somebody’s personal space or passing the boundaries of their comfort zone insofar as physical contact is concerned. Mattiasson and Hemberg (1998) explored intimacy in the care context. They suggest that touch is closely linked to care in that it can communicate understanding and empathy, give comfort and ease pain or be linked to treatment and care such as bathing a person or giving an injection. In its expressive form, it may alternatively be spontaneous, affective and not linked to any necessary task. Examples include stroking a person’s cheek, putting an arm around somebody or holding a person’s hand. The same act may be perceived and interpreted differently by different people and may be influenced by various factors such as the age and sex of the people involved. Some people with dementia may appreciate such contact and for them it may correspond to a need for intimacy in the form of genuine human contact. This may correspond to a psychological and social need as well as the need for physical contact. Others may perceive certain acts, involving touch as patronizing, infantilisation, disrespectful or irritating. People may experience touch and exposure of their body to others as shameful and humiliating. In such cases, they may feel threatened and behave in a defensive manner.

Different people have different attitudes towards trust and those of the carers might not necessarily correspond to those of the people they are caring for. Huss (1977) notes that the boundaries for touch vary between different cultures and that touch is often equated with sex unless it is clear that there is no connection between the two.

However, as dementia progresses, physical contact with the body by carers may become increasingly necessary. Mattiasson and Hemberg (1998) emphasise the importance of getting to know the person and how they feel about touch but also of being aware of the messages being conveyed through touch and intimacy. They suggest that it is when a person feels that they are being treated as an object of care rather than as a valued person that there is a risk of invasion of their personal privacy. An American study involving a random sample of 100 older nursing home residents revealed that touch was considered as positive when it was appropriate to the situation, did not impose greater intimacy than desired by the residents and was not considered as condescending (Hollinger and Buschmann, 1993). Negative touch was associated with procedures and ways which were considered as intimate and not corresponding to the needs of the individual.

Nonmaleficence

The avoidance of harm to the person with dementia

The major concern, with regard to nonmaleficence, is whether sexual activity or behaviour would cause harm to a particular person with dementia. Different types of harm are possible. For example, as people with dementia are potentially vulnerable to abuse and exploitation, there may be issues linked to the intentions of the partner in the activity or relationship (which might not necessarily be the spouse or stable partner of the person with dementia). Even if these are not "honourable" (e.g. the person is profiting from the person with dementia in some way), the person with dementia might not be considered as at risk of harm if they understand and accept those motives or feel that they are nevertheless benefiting in some way.

Everett (2008) provides an interesting case study of a situation involving a 75-year-old man living in a care home who regularly pays for the services of a 60-year-old escort. His adult children feel that this is harmful to his long-term financial security and not in keeping with his own past morals and religion. However, it is clear that their own values and concerns are involved as they also feel that the money being spent on the escort is coming out of their "rightful" inheritance and that the father's "sexual antics" are disrespectful to their deceased mother. The nurses in the home have concerns about his exposure to sexually transmitted diseases and for some, it offends their religious values. They are also concerned about not fulfilling their professional responsibility to protect all residents from harm. There are therefore arguments in favour of interfering in the situation but the man concerned may perceive potential benefit and potential harm differently. His perceptions are important when assessing his capacity but also whether the potential harm outweighs the benefits to him.

The risks of harm depend very much on how the man understands the impact of the expense on his long-term financial stability (including the continued ability to pay for the same standard of care as that he is currently receiving), his current beliefs and values, how he thinks his late wife would have felt about it, how he valued the relationship with her, how he values the relationship with the escort and whether he is taking precautions or can understand and assess the risks of contracting a sexually transmitted disease.

The avoidance of harm to people with dementia in relation to sexuality might also arise from a failure to respect their wish to abstain from sexual activities or relationships. Due to the age gap between most carers and people with dementia, staff may have more liberal views about older sexuality and relationships (including remarrying) than the people with dementia themselves. This is not problematic provided that staff do not inadvertently push their opinions and values onto people with dementia, thereby raising issues and creating dilemmas which would not otherwise occur (Mahieu et al., 2011). This may also create conflict if their views contradict those of family carers who may fear that the person with dementia is being unduly influenced. Unlike professional carers, family carers are part of the complex web of relationships which link them to the person with dementia and which may result in their own views being affected by loyalties, emotional ties and even greed.

The avoidance of harm or offence to others

Whilst the focus of the discussion must be on the interests of the person concerned, the case study highlights the importance of also considering harm to others and offence to others. According to Everett (2008), significant harm to others, if proven, could be considered as justifiable grounds for interference but this would not mean that the man's needs should be totally ignored. With regard to offence to others, such offence would also have to be considered as serious. In both cases, it is the seriousness of the harm or offence to others which must be proven. Even if proven, it would have to be shown that such serious harm or offence to others was greater than the reasonableness of the actions of the person allegedly causing such harm or offence. It is reasonable for a person with dementia, whether in their own home or in a nursing home, to have a relationship with or without sex with another person. It would be discriminatory to suggest that in principle (i.e. based on age or having dementia), they should not.

With regard to offence to others, some staff or residents in nursing homes might argue that certain sexual behaviour deeply offends them due to their strong religious beliefs. According to Everett, the reasonableness of sexual behaviour versus the seriousness of the offence to others should not be evaluated on the basis of standards set by a minority of people (either those who are for or those who are against). He states,

“Rather the reasonable person on the street, not the fanatic or devotee of pornography, should be used as the standard for determining whether a lonely, widowed individual living in residential care, who is seeking companionship in the form of a sexual relationship, is an offence to others that is serious enough to attract regulation or restriction” (Everett, 2008, p.93).

A problem still remains if the people who are opposed to the relationship provide care for the person concerned. Staff should not have to compromise their own ethical values. Everett (2008) suggests that in the context of residential care they be excused from providing care to that person. It is not clear whether this would be possible in all nursing homes. In the private domain, carers may not have that option.

Offence to others may also be an issue in the case of inappropriate sexual behaviour such as masturbation, unwelcome advances, self-exposure and sexualised comments, including swearing. This is not actually very common and there may be differences of opinion as to what constitutes inappropriate behaviour (Higgins et al., 2004). When this does occur, it raises issues about individuality, self-expression, privacy, beneficence, dignity and well-being in relation to the presumed "offender". However, within the relationship of care, the well-being of staff and other residents must be considered, along with a consideration of possible contributing factors which might cast a different light on the behaviour in question and help reduce its occurrence. On the other hand, in terms of equity, there should be similar expectations and house rules about what is, broadly speaking, acceptable behaviour within the context of communal living arrangements of people with and without dementia, albeit with a greater degree of understanding that some behaviour may not be intentionally disruptive or offensive in the case of the former.

Some of the behaviour discussed so far would not only be unethical but in some cases illegal (e.g. if carried out with deliberate intention to offend or cause harm or in a public place). People with dementia living in residential care are sometimes in a public area for the major part of their lives even though that place is also their home. Certain sexual behaviour, such as sadistic practices towards non-consenting adults, or any form of sexual act with children, should not be condoned irrespective of the level of dementia.

Risk

The principle of nonmaleficence is closely linked to perceptions of risk. In most cases, the main concern is about potential harm which means harm which may or may not occur and which has varying levels of severity. As it has not occurred, it can only be estimated. The level of the potential harm is also important when deciding what an acceptable risk is. According to the principle of proportionality, if the harm potential is very high, it is necessary to be cautious but if it is low or non-existent, greater risk can be tolerated. The relative importance of safety versus autonomy may be influenced by whether the person deciding is personally responsible for the person with dementia (Landau et al., 2010). Also, when someone has to decide what an acceptable risk is for another person, especially for someone who is potentially vulnerable, the level of risk tolerated is likely to be lower than it would be if they were deciding for themselves (Nuffield Council on Bioethics, 2009). Determining what is a high or low risk depends to some extent of each person's point of view. According to Lupton (2005), risk is socially constructed and value-laden. Consequently, there will be differences of opinion on this matter. On the other hand, people are entitled to take risks provided that they understand them and do not endanger others. This should also apply to people with dementia. The Mental Welfare Commission for Scotland (2006) considers that life is never risk free and that a certain degree of risk taking is part of good care.

The degree of harm to which a person is exposed as a result of a relationship may be linked to other factors which are due to the way that a nursing home or care is organised. Examples include the transfer of residents from one home or wing to another based on

the wishes of relatives or guardians, lack of transport facilities to enable socialising out of the home or of the possibility to obtain condoms discreetly.

Justice

According to the principle of justice, everybody in society should have the opportunity to take the same risks and to enjoy the same benefits. This reflects an ideal of equal opportunity and non-discrimination. Rules and practices which prevent people in residential care from using private areas in their own living areas to engage in sexual activities is a form of discrimination (Everett (2008). Discrimination is usually linked to power as the people who discriminate or allow discrimination to happen have the power to do so and those who lack power cannot prevent it. It is also linked to stereotyping as stereotypes of older people (including those with dementia) not being interested in sex or able to have a relationship make it easier to enforce situations in which they have no opportunity to do so. There are other groups in society which are expected to abstain from sexual relationships such as priests, nuns and monks in the Catholic Church. Although celibacy is imposed on them by the Church, they accept that restriction based on their beliefs and their choice to assume a particular role within the Church. This is not the same with people with dementia.

Sometimes, discrimination can be quite subtle. It may seem as though nobody is opposing a sexual relationship but an examination of the situation would reveal that there is no possibility for privacy (i.e. to be alone and not have everybody knowing what everybody else is doing). The environment may not be appropriate for sexual encounters or to share quiet moments with a friend (e.g. strong lighting, no curtains, single beds, no means of locking the door, nowhere to sit together, food and drink not permitted in the room, and perhaps worst of all, having a shared room). Slipping off unnoticed may be impossible in living arrangements where people sit together in a communal room all day long and eat together, and where it is the duty of staff to know where each resident is. In other words, it may be difficult to keep a private matter private and the fear of ridicule may make some people hesitant to express their feelings and sexuality publicly. Allowing this situation to persist could be deemed as discrimination and a subtle means of control which prevents people with dementia in residential care from having relationships.

The following sections address concepts which are relevant to the care ethics approach described by Mahieu and Gastmans (2012).

Privacy

Expressing ones sexuality and engaging in relationships are linked to autonomy in that people are making decisions about what they want to do and with whom. This may be accompanied by the desire to have privacy which is also an autonomous decision. However, privacy is also closely related to the care ethics as the desire for privacy is closely linked to individuality and one's relationship to others.

Based on a review of the literature Mahieu and Gastmans (2012) highlight three forms of privacy which are particularly important in residential care settings, but which might

also apply to people living at home with other people. First, there is physical privacy (i.e. being left alone, not having to see or be seen by others). Second, there is the privacy of information which means that other people should not be given information about a person without their permission. Third, there is the privacy of association.

In residential care settings, people have less possibility for physical privacy than in their own homes. Even if they have their own room, they may be obliged to spend parts of the day in communal areas, or staff may have access to their rooms. In some establishments, it may be possible to lock doors, but in some the only private space may be a cupboard or locker for possessions. This will be discussed in section 3. Even in people's own homes, people with dementia may find that relatives do not respect their need for privacy and therefore lack a place where they can engage in sexual activities. In both settings, people with dementia may lack the opportunity to have or acquire sexual materials due to lack of direct access to the post, computers or places to put the materials once acquired. There is also the privacy which is directly linked to the body and intimacy. People with dementia may eventually need help with acts which were formerly accomplished alone and in private (e.g. having a bath, getting dressed and going to the toilet). This may result in exposure of the body to other people and in some cases physical touch by relative strangers. Mattiasson and Hemberg (1998) suggest that the challenge for carers is to combine the provision of necessary care with respect for the right of the person with dementia to privacy and rightful wish not to be forced into a greater degree of intimacy than the care situation necessitates.

With regard to the privacy of information (i.e. confidentiality), the treatment and care of people with dementia is sometimes discussed in their presence but to other people as if they were not present and could be overheard by yet others who do not have sufficient privacy to be able to avoid hearing it. When the matters discussed relate to sexuality and relationships, this represents a substantial threat to the well-being of the people concerned. Older people in care homes often fear ridicule or infantilisation in connection with their sex lives and the relationships that they form with other people. In some cases, information may be revealed due to a failure to respect the principle of privacy, which a person has always deliberately kept secret from others but which may be difficult to hide in a nursing homes with limited opportunities for privacy. This particularly applies to people with gay, lesbian, transgender and bisexual identities, people having extramarital relationships and people who have always led very private lives. Breaching the right to informational privacy may lead to people being "outed" and this may have an impact on the way that they are subsequently treated by others but also lead to emotional stress and the fear of discrimination. Anticipated stigmatisation can be just as damaging as actual discrimination (Thornicroft et al., 2009).

The lack of physical privacy and informational privacy is quite common in residential care settings even amongst people who do not have dementia. A lady with multiple sclerosis stated,

“What I really miss here is my intimate sphere. There are constantly people walking to and fro and listening to conversations which have nothing to do with them. I haven’t once had the opportunity to cuddle or be intimate with my partner, which is actually a human right.” (translated from German, Weidner, 2012, p.14)

In some situations, private information about sexuality and relationships is disclosed to relatives. This might, for example include information about alleged sexually inappropriate behaviour towards staff or other residents, or the expression of sexuality in an inappropriate place. However, such disclosure fails to respect the right of the person with dementia to privacy. Such information could be disturbing to the relatives as well as to the person with dementia. In some families, sexuality is a taboo subject and relationships a private matter. In addition, knowledge about the sexual behaviour or relationships of a person with dementia may lead to a change in the way that people perceive that person, which could have a negative impact on their self-esteem and social dignity.

The issue with regard to disclosing such information to family members is not simply one of them knowing intimate details, in most cases, about their parent or partner. The disclosure of such information may, in addition, be linked to an expectation that the relatives should intervene or consent to certain approaches to manage “the problem”. In the case of long-term relationships, some staff may feel that they have a moral duty to inform the relative without dementia that their partner is having a relationship with another person. There are differences of opinion in the literature on this matter (Mahieu and Gastmans, (2012). Some people argue that there are no justifiable grounds to disclose such private information to relatives and that it should only be possible to do so if informed consent has been obtained. Others argue that it would be justifiable to share such details with relatives if the risk for potential harm outweighed the person’s right to privacy and confidentiality.

Privacy of association involves the right to choose friends, relationships and sexual partners. Often, this necessitates a certain degree of physical privacy and may be adversely affected by a lack of privacy of information. Difficulties may arise if other people have difficulty accepting that the person with dementia associates with a particular person or that they form any relationship at all. Objections may also be based on the type of relationship (e.g. a heterosexual person who, apparently for the first time, forms an intimate, sexual relationship with a person of the same sex, or vice versa in the case of gay couples).

Dignity

Dignity is linked in some way to most other ethical principles. In the context of sexuality, it is sometimes argued, especially by close relatives and friends, that certain behaviour is undignified as it is not in keeping with the person’s values and beliefs or is offensive to others and that this may affect the way other people value the person with dementia. On the other hand, it could be argued that respecting the fundamental human dignity of each person means allowing them to express their sexuality as this is a core part of their identity. It is possible that concerns about dignity involve some degree of projec-

tion whereby the person who is concerned about dignity projects their own feelings of shame and discomfort onto the person with dementia, when in fact the person with dementia is not ashamed or embarrassed and this is not necessarily due to a lack of awareness.

There may also be a link to vulnerability in that assumptions about behaviour resulting in loss of dignity are linked to beliefs that people with dementia are vulnerable and in this case need protecting from themselves. As people with dementia have varying degrees of capacity in numerous domains, they cannot be considered in blanket fashion (i.e. in a generalised way) as being vulnerable but only as potentially vulnerable. Consequently, even if certain expressions of sexuality or emotional involvement with others seem undignified, they must be considered from the perspective of the people with dementia expressing or experiencing them. There is a risk that perceived threats to dignity are evaluated on the basis of stereotypes, values, beliefs and sensitivities of other people.

There is a certain dignity linked to being considered an adult. Adult status is formally acknowledged in law in that minimum ages are set for the legal fulfilment of certain tasks such as voting, marrying, making a will and engaging in sex. The importance of being considered an adult is reflected in the decision made in Germany in 1992 to replace the practice of declaring people "entmündigt" with a more flexible system of guardianship (Bundesministerium der Justiz, 1996). According to Schönhof (2010), the term "entmündigt" has connotations of the loss of fundamental and basic rights which are acquired with adulthood and therefore has negative connotations. A person with dementia who is denied the right or opportunity to express their sexuality and have relationships or who must obtain the permission of others may feel infantilized and this may affect their dignity and self-esteem.

There are different communication patterns within families. Some speak openly about sexual matters but for many, these are private issues between couples and not to be shared with siblings or adult children. The discussion of intimate matters such as sexuality with the members of the family of a person with dementia could be considered as failing to respect the dignity of the person with dementia with regard to their position in the family.

Vulnerability

In geriatric nursing homes, elderly people are potentially vulnerable to abuse due to unequal power relations between staff and residents, unclear physical personal boundaries due to the need for assistance with intimate care, lack of privacy and in some cases cognitive difficulties. People with mental disabilities are also reportedly vulnerable to sexual exploitation and abuse (Schwab, 1992). People with dementia may also be vulnerable to financial and emotional abuse in the context of relationships. In the case of younger people with dementia, issues related to unwanted pregnancy and contraception must be considered (van Dyke, McBrien and Mattheis, 1995). Many people with dementia will have passed the age of reproduction but there are also women of child-bearing age who have dementia and some older men with dementia who are still fertile.

All people with dementia who are sexually active are equally at risk of sexually transmitted diseases. However, there is a risk of over-emphasising vulnerability, possible abuse and victimization, thereby overlooking other important issues such as sexual pleasure, well-being and quality of life.

Singularity

The principle of singularity focuses on the variety and uniqueness of each person (Mahieu and Gastmans, 2012). Everyone is different and one of the ways that such singularity is reflected is through each person's expression of their sexuality. People have different ways of managing their needs and desires. Disease affects each person differently and this may have a further impact on their sexuality and relationships. When talking about the sexuality of people with dementia, we have to bear in mind that it is different for each person. Each person with dementia, each relationship and each situation in which the relationship or act occurs, is different.

Historicity

Historicity reflects the historical dimension of human existence (Mahieu and Gastmans, 2012). It is about the importance of a person's life history, of knowing something about their background, what kind of a life they have led, how it has unfolded, what they have done, where they have been and things that have happened to them which were meaningful. An important aspect of each person's history might be their profession, if they had one, and their family. The nature of their relationships is also relevant to the ethical principle of relationality.

Relationality

Respecting relationality involves finding out what was and is important to the person with dementia with regard to relationships (Mahieu and Gastmans, 2012). This might include the importance of trusted relationships for that person's well-being, the nature of the relationships they have had in the past, the nature of current relationships (e.g. with spouses, partners and children), the importance of friendship and social exchanges and whether the interests of the person with dementia and potential partners or friends coincide. In keeping with the broader definition of autonomy proposed by the Nuffield Council on Bioethics (2009), enabling and fostering relationships is one way to promote autonomy. They further suggest that such autonomy in the context of relationships should not be understood in terms of balancing the autonomy of one person over that of another as people usually take into account what other people want when deciding what they want. This is therefore part of what is important to most people with regard to relationships.

Many people enter into residential care alone, leaving their partners behind or have no partner but the lifestyle they adopt as a single person living together with other people in residential care is not something they are familiar with or actively seek. It is therefore important to understand their experience of and attitudes towards relationships with other people.

Putting a care principles approach into practice is complicated. It is much easier to apply the biomedical approach but this is not as satisfactory in terms of outcome for the person (Mahieu and Gastmans, 2012). It takes a lot of thought to get into dialogue, to find out about the person and their history, their experience of and attitudes towards relationships and what makes them a unique individual. There is also a need to talk about sexuality and relationship and to take these issues seriously. Uncontrolled sexual behaviour is often the result of neglecting that issue with the result that it is expressed in an uncontrolled way. Sometimes by talking about it, there is already a solution. It may be an issue of loneliness and lack of intimacy.

2.3.4 Recommendations on the freedom to act according to individual attitudes, values and lifestyles

2.3.4.1 *Living in the community versus social segregation*

A range of living arrangements, support and services should be developed which are suited to the needs and preferences of people with dementia wishing to continue living in their own homes or in the community.

The possibility for people with dementia to continue living in the community should not be limited to their ability to adapt to existing structures, services and support which are not suited to their needs and preferences.

The use of assistive technology to enable people with dementia to continue living in the community should be further developed.

The right of people with dementia to access and use assistive technology at the time it would be most beneficial to them should be ensured.

2.3.4.2 *Practices within residential and semi-residential care settings*

Care establishments

Care establishments should strive to recreate the atmosphere through design, procedures and attitudes which is likely to make people feel at home.

Care establishments should respect and reflect the cultural diversity of the residents.

People with dementia living in or attending such establishments (referred to hereafter as residents) should be considered and treated as residents with rights.

The individuality of residents should be respected and as far as possible reflected in the way that they are treated.

Practices and ways of speaking to residents which are potentially demeaning, belittling, humiliating or infantilizing should be forbidden.

Healthcare professionals, auxiliary staff and managers should try to adapt the services and support they provide to the needs and wishes of the residents (as a group and, as far as possible, individually).

Opportunities for residents to smoke, be accompanied to the toilet or outside, or have a cup of tea/coffee should not be limited to set times of the day or to organised “rounds” unless there are justifiable reasons for this.

Any possessions which are personally valued by residents should, as far as possible, be recorded or labelled so as to avoid theft, confusion and misappropriation.

Any loss of possessions should be dealt with appropriately by the management of the establishment.

Care establishments should strive to provide opportunities for residents to participate in social life and maintain their habits and interests as far as possible.

Residents (people with dementia)

Residents should be provided with support and encouragement to do things for themselves if they are able and willing.

Residents should be permitted, within reason, to access light refreshments (e.g. a cup of tea or coffee and biscuits) at any time of the day or night unless there is a medical reason against this.

Residents should have the right to at least a minimum time outside in fresh air each day (weather permitting).

Residents should wear their own clothes and not be expected or obliged to share clothes from a common wardrobe with other residents.

Residents should have a private place (e.g. a locker or cupboard) which can be locked and the key or a double of the key entrusted to a member of staff if the person so wishes.

Residents should be encouraged to inform care staff of any exchanges of possessions which have been recorded or labelled so as to avoid future misunderstandings.

Residents should be allowed, if they so wish, to assist with simple tasks linked to the daily maintenance and running of the home.

Residents should, as far as possible, be involved in decisions relating to changes in routines or their living environment.

2.3.4.3 Sexuality and relationships

General

Informal and professional carers of people with dementia should be encouraged to explore their attitudes, values and beliefs about the sexuality of older people and people with dementia.

Negative stereotypes about the sexuality of older people and people with dementia should be challenged.

People with dementia should not automatically be considered as vulnerable to sexual or financial exploitation in the context of sexual or platonic relationships and/or marriage but the possibility of this occurring should not be overlooked.

Any cases of suspected abuse should be investigated and action taken if necessary.

Sexuality and relationship choices which are not consistent with the lifestyle and values of the person in the past should not be considered as conclusive evidence of undue pressure, incapacity or a threat to the person's dignity.

Care plans should address the sexual needs of people with dementia whether at home or in residential care.

Issues related to sexuality and relationships should be broached with sensitivity.

People with dementia should not be put under pressure to discuss their sexuality.

Assessments as to whether a person with dementia can consent to a sexual relationship should not be limited to capacity and nonmaleficence but should cover issues such as individuality, relationality and emotional and physical well-being.

All sexual identities (e.g. asexual, LGBT or heterosexual) and related practices should be accepted and promoted provided that they are in compliance with the law.

People with dementia should have the same right to enter into new LGBT relationships, continue existing LGBT relationships, engage in any sexual practices within the context of a relationship or otherwise, as do people who do not have dementia.

People with dementia should have the same right as other people to expose themselves to risk in the context of a relationship and to suffer the consequences.

Nobody should have the right to interfere in the relationship of a person with dementia unless there is a serious risk or evidence of abuse.

Care establishments

Establishments should have a clear, open and accepting policy towards sexuality and relationships involving residents with dementia.

Establishments should provide residents with appropriate and private areas in which to pursue relationships and express their sexuality.

Establishments should respect the right of residents to keep information about their sexuality and relationships private.

The sexuality and relationships of residents should be considered as care-related issues and not as problems.

Healthcare professionals should not impose their beliefs, morality and attitudes towards sexuality and relationships on residents in their care.

Care staff and other healthcare professionals should not be permitted to tease, ridicule or mock residents about their relationships or sexual activities.

Alleged offensive or inappropriate sexual behaviour should be considered on the basis of what a "reasonable person" might find offensive and not according to the religious or moral views of individual staff members.

Healthcare professionals should have access to a contact person from whom they can seek support and advice regarding the sexuality and relationships of residents with dementia and in the case of difficulties dealing with behaviour they find sexually offensive or inappropriate.

The needs, wishes and rights of residents to express their sexuality and form relationships should be given priority over those of carers and relatives.

Care staff should not automatically intervene to stop relationships or sexual activity which occur between a resident with dementia and someone who is not their long-term partner.

Residents should be supported in their attempts to manage their physical appearance and to engage in courtship practices.

Residents should have discreet access to methods of contraception and protection against sexually transmitted diseases, and to sexual, erotic or pornographic materials, other than images and items which are forbidden by law.

2.4 The restriction of the freedom to play an active role in society

Section 2.3 focused on restrictions of the freedom of people with dementia to behave and express themselves in accordance with their personal values, beliefs and preferences. Section 2.4 also addresses such issues but focuses on those which have implications for the freedom to play an active role in society (i.e. politically, economically and socially).

The first issue addressed is that of voting which represents a civil act (and even obligation in some countries) and marks the participation of adults in the democratic societies in which they live. This is followed by a brief discussion of restrictions of freedom of people with dementia related to decisions with legal implications. The example of marrying is briefly addressed, which follows on from the discussion about relationships in section 2.3 but focuses on the ethical issues linked to the legal implications of marriage and of the assessment of the capacity to marry rather than on the personal and emotional issues involved. There are several types of decision with legal implications (see subsection 2.4.2) but it was decided to discuss that of making a will in more detail as it is unique in that it often represents the final expression of a person's will, extending beyond that person's capacity to express such will and is often only made known and in some cases challenged after the person's death.

The section ends with a discussion about the ethical implications of driving. Driving is also a very personal matter. For some people it is a pleasure, for others a necessity. Giving up driving is often equated by people with dementia with a loss of freedom and independence. In many cases, it has a negative impact on their ability to play an active role in society, resulting in social isolation and exclusion. Driving also has legal implications based on the need to protect drivers and other members of society from harm.

2.4.1 Voting

2.4.1.1 *The current situation and probable future changes*

In Belgium, Greece, Italy, Luxembourg, Cyprus and Latvia, people are obliged to vote but in Greece and Luxembourg people over the age of 70 and 75 respectively are not (Inclusion Europe, 2011). People with intellectual disabilities do not participate to the same extent in general elections as the rest of the population. An estimated 20% participation rate of people with intellectual disabilities was observed in Sweden in 1998 and in the UK, the percentage was estimated at 31% in 2010.

In some countries, such as Hungary, people were until recently automatically deprived of the right to vote if under any kind of guardianship. However, a landmark ruling at the European Court of Human Rights ruled that automatic disenfranchisement was contrary to certain European and international agreements to which Hungary was party.

In 2012, the Council of Europe adopted a recommendation on the participation of people with disabilities in political and public life. These recommendations are not legally

binding but were adopted by consensus by all 47 member states. Moreover, the European Court of Human Rights often cites such recommendations in its judgements. This recommendation is particularly important as it builds on the UN Convention on the Rights of Persons with Disabilities, calling for European governments to ensure that their legislations overall does not discriminate against persons with disabilities in political and public life. All adult citizens with disabilities should have the right to vote, the recommendation states, adding that laws should be 'devoid' of discriminatory provisions. It specifies that all 'persons with disabilities, whether they have physical, sensory, or intellectual impairments, mental health problems or chronic illnesses, have the right to vote on the same basis as other citizens, and should not be deprived of this right by any law limiting their legal capacity, by any judicial or other decision or by any other measure based on their disability, cognitive functioning or perceived capacity' (MDAC, 2011).

According to Redley, Hughes and Holland (2010, p.466), "Voting is a political right, not a matter of competence to make decisions". Consequently, people should not be excluded from voting just because they have a disability. The new Council of Europe recommendation suggests that there should be no necessary legal capacity to vote. Whether a person has the necessary physical and mental capacity to vote is a separate issue. Apart from making a wise, informed decision, which many people fail to do, voting requires the ability to get to the polling station on time and indicate one's choice in such a way that it will be officially recognised as being valid by those responsible for the organisation of the election and the counting of the ballots. In some countries, it is possible to vote by post.

2.4.1.2 *The capacity to vote*

There is limited literature on the capacity to vote. Appelbaum, Bonnie and Karlawish (2005) have developed a tool to measure voting capacity called the Competency Assessment Tool for Voting (CAT-V). They found a strong correlation between the severity of dementia and the capacity to vote. In France, legislation recently changed from people with mental disorders needing exceptional authorisation to vote (i.e. they were otherwise barred from voting) to the situation whereby an individual/special ruling is needed to deny the right of a person with mental disability to vote. However, in the light of the Council of Europe ruling, issues related to the capacity to vote become less important as it is likely that people with dementia will, in the future, have the right to vote irrespective of capacity.

2.4.1.3 *The desire to vote and possible benefits*

A study by Bullenkamp and Voges (2004) in Mannheim (Germany) involving 110 participants (out of 215 community dwelling people with mental health problems) found that voting led to enhanced social engagement and self-esteem. Similarly, a diagnosis of dementia has not been found to preclude the desire or ability to vote (Karlawish et al., 2004). Voting is therefore linked to the principles of beneficence, quality of life, social inclusion. Failure to allow and enable people with dementia to vote fails to respect their autonomy and is discriminatory in that it does not permit them to participate in society on an equal basis with other citizens.

2.4.1.4 Obstacles to voting faced by people with dementia

Deprivation of the right to vote by care staff

According to a UK study (reported in Regan, 2011), residents in residential homes for elderly mental infirm (EMI) in the UK have been denied the right to vote on the basis of an assessment of their capacity by nursing and residential care home staff. Consequently, people with dementia in nursing homes have additional obstacles to voting compared to those living in the community. Those who are living in their own homes in the community might simply go and vote whereas those living in residential homes may be subjected to assessments of the capacity. This amounts to discrimination and a possible abuse of power. This also raises the question of the competence of nurses and care staff to evaluate the capacity to vote.

Blocking access to political information

Staff may also be involved in a form of gatekeeping in terms of regulating access to people with dementia by politicians and their representatives trying to drum up support for their party and access to television emissions and other information from politicians (e.g. leaflets and pamphlets) which would inform people with dementia about what the different parties are offering.

Computerized voting methods

In some countries, computerized voting systems are now used. This may be off-putting not only to people with dementia who may fear being unable to use the system but also to older generations who are not familiar with computer technology. De Cauwer (2005) asked 41 people with dementia living in the community about their experience of the 2003 federal elections in Belgium. The majority (i.e. 28) of those asked had voted. Amongst those who did not vote only 1 was put off by the computerised voting (according to that person's carer). However, most needed assistance using the computerised system which according to De Cauwer (2005) raises concerns about confidentiality and suggests that the use of such systems might in fact dissuade people with dementia from voting. There is also the issue of undue influence in that the person who helps (e.g. a relative or voting official) might exert influence on the voter or trick them into voting for a different candidate.

2.4.1.5 Recommendations on voting

There should be clear governmental guidelines on how to maximise the potential for people with dementia in long-term care to vote.

Transport issues must be considered for people with dementia to ensure that they can get safely to and from the polling station.

A trained and neutral person should be made responsible for overseeing/providing assistance to people with dementia at the polling station on an interpersonal basis and by ensuring that the procedure and environment is dementia friendly.

In keeping with the principle of reasonable accommodation, it should be possible for an accompanying person to enter into the voting booth with the person with dementia in order to provide assistance, if requested by the latter.

Absentee voting (i.e. from a distance) should be possible for people with dementia (especially those in residential care or hospitals). This raises the issue as to who fills in the ballot and whether it is posted.

Managers of care homes should ensure that residents are not prevented from voting due to administrative details linked to their current place of residence (i.e. they may need to be enrolled on a different voting register. This depends on the regulations in each country).

Electoral officials should facilitate voting in care homes by enabling registration and voting in large care homes, which could bring residents from other homes for the same purposes at the appropriate time. The necessary funds should be provided to electoral officials to make this possible.

Residents with dementia in care homes should have access to timely information about upcoming elections.

Residents with dementia in care homes should have access to campaigning political candidates (if they wish such contact) and to relevant information available to the public during the election campaigns.

Residents with dementia in care homes or hospitals should have the right to ask for assistance with voting from any person they wish and not be obliged to be assisted by a specific approved assistant.

Care homes and hospitals should have a person available to assist residents and patients desiring to vote, should they wish to ask for such assistance from that person. The training and assistance provided by that person should be provided on a non-partisan basis.

It should be possible for people with dementia to make an advance directive for voting (especially useful in the case of people who vote on a lifelong basis for the same party) but should have the right to cancel that specific advance directive at any time, even when they are judged as lacking capacity.

Nobody should be allowed to vote on behalf of a person with dementia unless such authority and guidelines were given by the person with dementia when they had the capacity to make such a decision, and it is legal to do so.

A person should be allowed to go into the voting ballot with the person with dementia to assist with the process of voting (if the person with dementia clearly wishes this).

2.4.2 Making decisions with legal implications

Some decisions have legal implications (i.e. have consequences which are determined by the law). A minimum threshold of relevant capacity may be required to make such decisions. Examples include marrying, making a civil partnership, divorcing, making certain commercial contracts, accessing legal aid/justice (e.g. defending oneself in court or taking out a law suit against someone), making a will or a donation and handling one's finances. Maintaining the right to make such decisions is closely linked to respecting individuality, personhood, autonomy, privacy, equity and social inclusion. However, the main emphasis is often on the financial implications of such decisions.

Taking the example of marriage, the legal implications of this are that couples are bound to each other under law. It is a legally binding contract and the assets and liabilities of the two parties are considered as joint (Woolley and Co., 2008). This in turn has an impact on inheritances. Legislation in most countries specifies that individuals wishing to marry must have the necessary capacity to do so (Alzheimer Europe, 2010). The legal threshold for such decisions is generally quite low (Peisah et al., 2008) and focuses on an understanding of the nature of marriage and the expectations and responsibilities associated with it (which have developed over time and correspond to cultural and sometimes religious beliefs about relationships and families). Financial matters are rarely referred to directly.

Financial abuse may occur as a direct consequence of the changes in the financial responsibilities of the couple. A person with dementia might, for example, be persuaded to enter into a marriage based on a deficit of judgement, through passive acquiescence or failure to understand the implications it would have for them (Peisah et al., 2008)). This could equally apply to other contractual agreements with legal implications. The law seems to focus on the protection of financial rights. This is given greater importance than ensuring other aspects of people's well-being. Protection against financial abuse could be considered as reflecting the principles of beneficence and non-maleficence. However, there is a risk that it is primarily the family's financial affairs which are being protected and not those of the person with dementia. Inappropriate or out-dated legislation, which does not take into account the task specific nature of capacity, fails to respect the autonomy of people with dementia. In some cases, restrictions may serve the interests of other individuals who may stand to benefit from the loss of a particular right (e.g. to remarry, sell property, make a donation or change a will). Similarly, the loss of the right – and/or opportunity - to access directly legal advice and representation (i.e. by oneself rather than with the approval or assistance of a legal guardian) may render people with dementia more vulnerable and open to abuse. A typical fear that people have of dementia is of not being listened to or taken seriously (Boustani et al., 2008). The loss of the above-mentioned rights may be perceived by people with dementia as evidence of this.

Being deprived of the right to make decisions with legal implications should be based on evidence of incapacity and justified on the grounds that it is in the person's best interests (not solely the person's best financial interests). In some countries, the establishment of

a particular guardianship measure can have an automatic consequence on the right to make certain decisions. This is based on a one-off assessment of capacity, usually established by a legal court with the assistance of relevant experts (e.g. a psychiatrist, geriatrician or neurologist depending on the country). Once the person has been declared legally incapacitated (a decision which is often made public), they are prevented from making certain decisions with legal implications irrespective of whether they have the capacity for individual decisions. This constitutes a potential disregard of a person's autonomy.

In some countries, a person who is under guardianship must obtain authorisation to make certain decisions which are legally binding. In Luxembourg, for example, a person who is subject to curatorship cannot marry without the authorisation of the curator or tutelary judge, and a person who is subject to curatorship cannot marry without the authorization of the "family council". This has implications for the power relationships within families, and renders the person in question open to abuse from relatives with conflicting interests. The process is also patronizing and infantilizing. Fortunately, there has been a recent move towards fairer forms of guardianship in which guardians are expected to promote the person's remaining capacities, provide decision-making support when necessary and take into consideration the person's wishes when deciding on their behalf.

In the following section, an example of a decision with legal implications, namely that of making a will (sometimes called "a last testament"), is discussed in more detail.

2.4.2.1 Making a will

Making a will differs somewhat from other decisions with legal implications as it can be a very personal decision which is often made in private, sometimes unknown even to close relatives, and for which capacity is often queried retrospectively. Having the right to make a will means being free to dispose of one's assets and treasured belongings as one sees fit. It is an act which has legal implications but can also be an expression of one's character and an opportunity to make a last statement. In some ways it is similar to some of the acts mentioned above which have legal implications in that it requires that a person is recognised as having the necessary and relevant capacity to carry out that act (i.e. to make a will). In some respects, it is different because the legal implications only occur after the person's death.

Testamentary capacity – the criteria

A person is generally considered to have testamentary capacity if they fulfill certain criteria, namely that they:

1. Understand that they are disposing of their money, possessions and assets.
2. Are of sound disposing mind (i.e. can recognise the extent and character of the property and dispose of it with understanding and reason).
3. Can recall and understand the claims of potential heirs.

4. Do not have a disorder of the mind, such as delusions or hallucinations, which would influence their decisions.
5. Are not subject to undue influence or pressure from others.
6. Understand that making a new will revokes any previous wills.

Some authors describe testamentary capacity as the lowest level of competence (less than entering into a contract, for example, in which the adverse party seeks an advantageous position). A counter argument is that the testator may have an adversarial relationship with other members of the family or there may be one between two parties contending for the inheritance (Bursztajn and Brodsky, undated). Also, testamentary capacity is situation-specific. Consequently, the level of cognition needed for simple, uncomplicated wills is much lower than that needed for more complex legacies (e.g. involving larger sums and complex family dynamics) (Shulman et al., 2007). Davis (2005) suggests that nowadays the nature of possessions is more complex than it was in previous centuries. Some people have property managers and advisors and may not even know their shareholdings or real estate details.

With regard to recalling and recognising the claims of potential heirs, it must be borne in mind that people with dementia may eventually have difficulty recognising their friends and relatives. Whether a person must simply have knowledge that they have relatives who may have claims to their estate or actually be able to physically recognise them is not clear.

The condition that testators should not have a disorder of the mind which could influence their decisions raises a few issues such as lucid intervals, delusions and hallucinations and unwise decisions. A lucid interval has been defined as a period of relative mental clarity between periods of irrationality, especially in organic mental disorders such as delirium and dementia (Mosby's Medical Dictionary, 8th edition, 2009). With regard to delusions, Davis (2005) differentiates between paranoid ideation (which is often a suspicion which can be reasoned with or challenged) and a delusional belief (which tends to be fixed and resist reasoning or being challenged). He states that neither necessarily corresponds to a lack of testamentary capacity. The will of a person known to have experienced delusions may be challenged but the type of delusion is important. Testators must only be free of *interfering* delusions and this is not dependent on the absence or presence of a psychiatric diagnosis.

The capacity to make a will does not preclude the right to be eccentric, to make decisions considered as weird or to make stupid or unwise decisions. In the case *Smith vs. Smith* (1891), it was decided that "stupid error" in reasoning or drawing conclusions was not proof of a lack of testamentary capacity. Similarly, there is also a long-established principle that capable testators have the right to dispose of their possessions and assets as they see fit even if motivated by malice, pride or bizarre reasons. People with dementia with testamentary capacity should not be denied these rights. However, in the case of dementia, due to stereotypes about lack of capacity, it may be more difficult to prove retrospectively that unwise, eccentric or unexpected decisions are not signs of incapacity.

With regard to undue pressure, claims are sometimes made that someone has exerted undue pressure on an older or vulnerable person in order to benefit from some of their inheritance. Hall et al. (2009) point out that undue pressure often occurs in situation involving a power imbalance or dependency. The term “undue influence” refers to something which destroys the free agency of the testator and substitutes that of another (Perr, 1980) (e.g. by means of coercion, compulsion or restraint resulting in the wishes expressed not reflecting those of the testator). Wishes may also be influenced by fraud or deception. Perr (1980) suggests that less influence may be needed to control the will of a person whose functional abilities have been severely impaired by mental illness or a physical condition affecting mental functioning.

Establishing testamentary capacity

The capacity to make a will is one form of capacity amongst others. Lack of capacity in other areas of life is not sufficient proof of the incapacity to make a will. Nevertheless, it is possible that the will of a person who had dementia when it was written might be challenged.

In *Kenwood v Adams* (1975), the golden rule was established which stated that the capacity and understanding of the testator ought to be witnessed or approved by a medical practitioner whose examination and findings should be recorded and preserved. This is described as a precaution and not considered as sufficient proof of testamentary capacity but highly regarded and likely to make it very difficult to challenge, on the grounds of incapacity, the will of a person who did this.

Bursztajn and Brodsky (undated, p.5) raise the issue of the involvement of treating physicians in assessments of testamentary capacity (particularly in situations involving deathbed revisions of wills). The desire to relieve the patient’s suffering may preclude necessary objectivity. The clinician may confuse the capacity to consent to treatment with the capacity to dispose of one’s possessions. Whilst medical professionals are often asked to determine whether a person has or had testamentary capacity, there is little guidance and a lack of appropriate tools to assist them in this task.

Challenging testamentary capacity retrospectively

It has been suggested that the growing number of people with dementia creates a fertile ground for challenges to wills (Shulman et al., 2007). A will made by a competent person cannot be invalidated on the grounds that they lacked capacity at the time of their death. Similarly, insanity *per se* does not necessarily invalidate a will (as explained above).

According to Kahn et al. (undated), clinicians in the UK (England) are regularly asked to assess retrospectively patients’ testamentary capacity. It is claimed that decisions based on retrospective assessments are often made “on the balance of probabilities” which is a lower standard of proof than “beyond reasonable doubt” which is used in criminal cases. This might be different in other countries. Often, the clinicians have to rely on limited evidence from medical files and prior scores on the MMSE. The MMSE is not a measure of

testamentary capacity but it continues to play an important role in retrospective assessments of testamentary capacity.

Davis (2005) claims that most wills are challenged on the basis of the testator's capacity to identify, evaluate and discriminate between the respective strengths of the claims of their potential beneficiaries. Shulman et al. (2005) reviewed reasons for wills being challenged and found that the main reason was a dramatic or radical change from a previous will (72% of cases). The second main reason was alleged undue influence (56% of cases). In just over half of these cases, the testator had no children and in almost half of cases the will being challenged had been written less than one year before the testator's death.

Often challenges are made years after the person's death when memories of the person have faded. Some people may recall the person in the time leading up to their death when they had few remaining capacities and not at the time the will was written when that person may have had full testamentary capacity.

Redmond (1987) suggests that there is a discrepancy between the assessment of competence at the time a will is made and the retrospective assessment of competence in terms of information provided, people involved and access to supporting documents. The initial assessment is often made by people who have little if any knowledge of the testator. There is a basic presumption that the person has testamentary capacity. When a will is challenged, medical records are consulted, relatives and expert witnesses are interviewed who knew the person well. It is much easier to prove that a person has capacity whilst they are alive than retrospectively. Nevertheless, Maki-Petäjä-Leinonen (2010) points out that in Finland retrospective challenges to wills by family members are rarely successful as it is difficult to obtain evidence of lack of testamentary capacity. Clearly, there may be differences in how retrospective challenges to testamentary capacity are dealt with in different countries and how successful they are likely to be. Some authors such as Hall (2009) and Bennet and Hallen (2004) suggest that people with dementia take precautions to help reduce the likelihood of their testamentary capacity being successfully challenged after their death, and provide guidelines for healthcare professionals who are asked to make retrospective assessments of testamentary capacity. These are included in the recommendations below.

2.4.2.2 Recommendations on making decisions with legal implications

General

There should be no automatic loss of the freedom to make decisions with legal implications based on a global assessment of capacity or on the establishment of a guardianship measure.

The legal practice of declaring a person legally incompetent (globally rather than in relation to specific tasks) should be abolished.

Nobody should be permitted to make a decision with legal implications on behalf of a person who can demonstrate that they have the capacity to take that specific decision themselves or with the appropriate level of support.

There should be an independent authority, either a person or an organisation, to whom any person who is denied the right to make a decision about their own life can appeal. They should have access to an independent advocate to assist them in this.

Testamentary capacity

Health care professionals who are asked to assess testamentary capacity, either currently or retrospectively, should check whether there are/were suspicious circumstances such as radical changes from previously expressed wishes or wills, and possible signs of undue influence/pressure, deceit or fraud from members of the person's entourage.

The stage of dementia and/or evidence of delusions should only be taken into consideration if they are considered relevant to decisions made by the testator in their will.

Expressions of individuality, eccentricity, unwise decisions or personal/emotional grounds for decisions should not be considered as evidence of testamentary incapacity (i.e. any more than they would be for a person who did not have dementia).

Where there is a suspicion that a will might be challenged on the grounds of lack of testamentary capacity, the discussion, drafting and signing of the document should be visually recorded (e.g. on videotape or digitally) subject to the consent of the testator.

Testators who are concerned that their testamentary capacity might be challenged retrospectively should consider obtaining expert medical proof of their capacity, bearing in mind that this might also lead to closer scrutiny of such capacity.

2.4.3 Driving

The ethical issues related to driving are mainly related to autonomy, beneficence/non-maleficence, confidentiality (medical secrecy) and quality of life.

2.4.3.1 *The importance of driving for people with dementia*

Not everyone with dementia is or was a driver. Some have never had a driving licence or car. Others may have already sold their car for other reasons (e.g. based on the cost of running a car or as a result of moving into a small community). Those who are drivers are likely to be faced at some point with the realisation that they can no longer drive safely or with the obligatory cessation of driving.

Like many other people without a car, people with dementia who are obliged to stop driving may have to rely on public transport, which is limited in some areas (e.g. one bus per day and no train station). In addition, dementia often entails a range of impairments which may render the use of public transport impractical. For example, people with dementia may have problems handling money (but need to pay fares), have problems

with gait (but need to get on and off a bus, travel whilst standing up and move along a moving bus) and difficulties with planning and disorientation in time (but need to work out timetables and organise their time). The loss of the right to drive may therefore have a serious impact on their lives and also on the lives of partners who do not drive.

Loss of the right to drive may result in less out-of-home activity, social isolation, depressive symptoms and even increase the risk of entry into residential care, all of which may affect a person's physical and mental well-being as well as their quality of life (Freeman et al., 2006; Marottoli et al., 2000). In some cases, loss of a driving licence may affect the ability of the person with dementia to contribute towards society through paid or voluntary work.

In addition to the practical and functional aspects of mobility, older people and people with dementia often appreciate the qualitative aspects of driving. Many older people, for example, enjoy driving and consider it a hobby and even a motivating factor in their lives (Arai et al., 2010). People with dementia have described driving as being important to their quality of life (Adler and Kuskowski, 2003). Arai et al. (2010) therefore suggest that in addition to finding solutions to the mobility aspect of driving (i.e. how to get from A to B), attempts be made to find alternatives to the qualitative aspects of driving (e.g. by increasing the opportunities for social interaction and helping people to find something else that is meaningful and brings quality to their lives).

With reference to older people's cessation of driving (i.e. including many people with dementia), there are psychological issues to be considered linked to the disruption of social roles, to the perceived threat to one's person's identity, loss of self-esteem, loss of independence, loss of spontaneity and becoming dependent on others (Fonda et al., 2001; Ragland et al., 2005; Rudman et al., 2006; Whitehead et al., 2006). If the loss of the right to drive was influenced by the advice or persuasion of other people (such as relatives, friends or the general practitioner), there may also be resentment and a deterioration in the relationship between the person with dementia and those people (Haltiwanger and Underwood, 2011).

2.4.3.2 *Are people with dementia who drive a risk?*

It is frequently argued that people with dementia are potentially dangerous to themselves and others. Sometimes, this claim is restricted to people with dementia who have lost the capacity to drive but sometimes it is suggested that a mere diagnosis of dementia indicates that a person might at some time represent a danger when driving and as it is not known at what point this occurs, they should be prevented from driving. It has been estimated that there is an eightfold risk of car accidents of people with mild or moderate Alzheimer's disease (AD) compared to drivers who do not have AD (Bieliauskas, 2005; Friedland et al., 1988).

However, as Burns and Harris (1996) point out young male drivers have the highest risk of car accidents with the odds of them being involved in accidents being comparable to patients in the fourth year of progressive cognitive decline. In Japan in 2008, older

drivers were the third highest risk group after those in the 16-24 age group (the highest risk group) and those in the 25-29 age group (the second highest risk group) (Arai, Mizuno and Arai, 2010). The order of risk per age group was identical in a survey carried out in New Zealand (Hoggarth et al., 2011). Nevertheless, as young male drivers are not prevented from driving, it could be considered discriminatory to prevent people diagnosed with dementia from driving. Also, the measurement of injuries and deaths in different age groups is perhaps misleading as their incidence may be inflated by the tendency for older drivers to be more physically fragile than younger drivers resulting in the same kind of accident having more serious physical consequences (Hoggarth et al., 2011). Also, being involved in a car accident should not be confused with being responsible for a car accident.

According to Anstey et al. (2005), older drivers are more vulnerable to crashes. Some physical limitations, which are more common in older people, may affect driving safety. Examples include arthritis, problems with eyesight, slower reactions times, specific disease and certain medication. Anstey et al. (2005) further suggest that some degree of cognitive decline linked to normal ageing (particularly with regard to attention) may affect the ability to perform complex tasks such as driving. It is generally agreed that dementia is a risk factor for driving (Brown and Ott, 2004; Dobbs, Carr and Morris, 2002). Compared to the general population of drivers, those who have dementia are considered as being at increased risk of unsafe driving (Man-Son-Hing et al., 2007; Uc et al., 2006), although a few studies suggest that crashes are not frequent (Carr, Duchek and Morris, 2000).

However, Hoffman Snyder (2005) points out that different types of dementia do not all present the same type or level of risk for driving. She describes the different risks associated with cortical, subcortical and mixed types of dementia. It is important to understand these differences when considering whether a person is fit to drive and when designing tools to assess driving capacity.

2.4.3.3 Stopping driving

Arguments in favour of allowing people with dementia to drive focus on their right to lead autonomous lives and the fact that a diagnosis of dementia does not imply the automatic loss of driving capacity. But at what point does an individual driver with dementia become an actual risk?

Often, people with dementia make an autonomous decision to stop driving and use public transport or take measures to maximise their safety, such as sticking to quiet, familiar roads, not driving at night or in the rain or snow, or only driving when accompanied (Adler, 2010). A counter argument is that people with dementia may lack insight and consequently be unaware of the point at which they lack the capacity to drive. Approximately, 40 to 50% of drivers with dementia continue driving following diagnosis (Carr, 1997; Lloyd et al., 2001). Driving represents a last freedom and expression of autonomy for some people. It is an integral part of their lifestyle and enables some to avoid isolation and remain part of the community. Driving may also be symbolic of adult status. It

is therefore possible that some people will continue driving in full knowledge that they are losing the capacity.

When people with dementia are not willing to stop driving and ignore possible requests from their relatives and friends, the latter sometimes take measures to stop them such as hiding keys, disabling the car, making the person believe it is out of order, parking it out of sight or even selling it if they have the right. Such measures might be considered as patronising, failing to respect the autonomy of the person with dementia, dishonest and deceitful or on the contrary, as protecting a person who lacks insight into the dangerousness of their behaviour. If the person is fully aware that they lack driving capacity but refuses to stop, such measures might still be ethically justifiable if aimed at protecting other people. In this context, whilst many people consider driving as a right, it has also been described as a societal privilege (Hoffman Snyder, 2005) granted on the condition that people abide by the laws governing driving.

In accordance with the principle of non-discrimination, concrete action is needed to provide a framework in which people who have lost their driving licences as a result of dementia are not excluded from participating fully in society. These might be the same measures designed to ensure the participation and social inclusion of other non-drivers but additional measures might be needed to ease the transition from being a driver to losing one's licence based on dementia, and also to address the specific needs of people with dementia who may have become dependent on having a car.

In Appendix 2, James McKillop, who has been diagnosed with vascular dementia, describes his experience of driving and the impact of losing the right to drive.

2.4.3.4 Formal assessment of driving competency

There are several ways to approach the assessment of driving capacity, such as neuropsychological/cognitive tests, on-road testing, driving simulation and carer reports. Assessments of driving competence must cover not only the capacity to drive (the skills required) but also whether the person can drive safely. There seems to be a general consensus in the literature that cognitive tests alone should not be considered sufficient to withdraw a person's driving licence but that they can be helpful in deciding whether to refer a person with dementia for an on-road test (Lincoln et al., 2010).

General practitioners (GPs) may be responsible for determining whether a person is medically fit to drive. This means that the person has no medical condition which would interfere with the ability to drive or if they have, and it has the potential to interfere with driving, this is not currently the case for a particular person (Hoggarth et al., 2011). If the GP declares that a person may be unfit to drive, this might be followed up by a formal assessment (but maybe in some countries not). However, so long as the GP does not signal any problem, the person is likely to continue driving. According to Hoggarth et al. (2011), the capacity to drive can only be assessed through observation of a person driving on a road and is impossible to assess in a GP clinic unless there are extremely reliable reports (e.g. from the traffic police) about the person's unsafe driving behaviour.

Many people who drive safely would have a problem if they had to retake the test as nowadays, there are also tests for theory. If this involves the ability to write or manipulate computerized gadgets, this would be unfair as it would involve testing a capacity which is not actually relevant to the practice of driving. The ability to pass a test is not what should be being measured by a test for driving competence.

Capacity is task specific and affected by a range of factors (e.g. the environment, the time of day and the situation). Incapacity in one domain does not necessarily imply incapacity in another domain. However, tests for driving competence involve a range of additional tasks which might have a negative impact on driving performance on the day of the test (e.g. finding the place of the test, finding the right room in a huge hospital complex which is badly signposted and being given lots of forms to fill in first). The associated challenges are not part of the capacity to drive.

It could be argued that, in real life, driving will sometimes be preceded by disturbing events or conditions but this cannot be presumed. A person with dementia has the right to drive when they feel up to it. In some types of dementia, the capacity to drive might fluctuate. To draw a parallel, a person would probably decide not to drive when suffering from severe migraine. A counter argument might be that the person with dementia might lack insight as to when they have driving capacity. However, the fact remains that a test of driving competence should measure driving competence and that alone. A medical driving assessment used in New Zealand takes 45 minutes and is "on the road". It is not aimed at ensuring a stringent observance of road rules and people are therefore not penalised for driving errors commonly made by drivers amongst the general public (Hoggarth et al., 2011).

When a person is learning to drive, they can try to pass the test as many times as they like. In some cases, they may fail one day and succeed a couple of weeks later. It is unlikely that their driving capacity improves in two weeks. Driving tests are stressful and in the case of dementia, it may be perceived as one's last chance and that one's independence is at stake. This must surely add to the stress of being tested. For this reason alone, people with dementia should be entitled to at least a second test. As this is a medical issue, the cost of assessment should be covered by state health insurances. If not, the cost should be low and in no way comparable to the costs paid by people acquiring a driving licence for the first time. Otherwise, a person could lose the right to drive (even though perhaps still fit to drive) as a result of not having the financial means to prove otherwise. This would amount to discrimination against people on a low income. As older people tend to be on lower incomes, this would amount to ageism.

If a person with dementia passes an on-road driving assessment, they may nevertheless experience difficulties driving at some point in the future, even in the very near future. Fox et al. (1997) found that 4 out of 7 people with dementia failed a second driving assessment, taken six months after the first. Conclusions cannot be drawn from such a small number of cases but a few other researchers recommend on-road assessment every six months (Adler et al., 2005; Duchek et al., 2003).

2.4.3.5 Confidentiality vs. safety

In some countries, GPs are legally obliged to report people who are considered unfit to drive (e.g. due to dementia) or who have been diagnosed with dementia to the vehicle licencing authorities or the police. This could be considered as unethical as it interferes with the principle of confidentiality of medical information. The question is – “Is it a medical practitioner’s ethical obligation to check whether a person with dementia is still driving or only to react if it comes to their knowledge that the person is a driver?”

Reporting a patient to the relevant authorities may affect the relationship of trust between the doctor and the patient, violates the principle of patient confidentiality and may result in patients breaking off contact with the doctor (Hoffman Snyder, 2005). Failure to pursue a diagnosis (if people feel that they risk losing their licence) may result in the loss of the potential benefit of services and treatment for dementia.

2.4.3.6 Recommendations on driving

A diagnosis of dementia, a low MMSE score or a driving offence should not be considered as proof of incapacity to drive.

Tests to measure driving capacity should involve on-road testing and not rely solely on computerised, paper, verbal or other forms of assessment.

GPs should discuss the topic of driving with any of their patients known to have dementia.

If, having first discussed the issue with the patient, the GP is concerned that a patient with dementia who is unfit to drive is still driving, they should take the necessary legal or administrative steps for that person to be tested.

The driving capacity of people diagnosed with dementia should be assessed on a regular basis (e.g. every six months) with increasing frequency as the condition becomes more severe.

Should the person with dementia fail a test to assess their driving capacity, they should be permitted to retake the test before any permanent measures are taken to limit their right to drive, but should not be allowed to drive until/unless they have passed that test.

Measures to restrict the right to drive should be appropriate and proportionate.

Governments should consider the possibility of restricting driving depending on individual cases and the nature of the incapacity or difficulty.

Driver refresher courses for older drivers should be recommended (e.g. by driving associations such as the AA or ADAC) in an attempt to raise awareness about safety issues.

Guidance for older people should be provided on signs to look out for which might indicate that their capacity to drive has worsened.

In accordance with the principle of non-discrimination, governments should take measures to ensure that people with dementia are not prevented from full and effective participation in society on an equal basis with others as a result of the loss of the right to drive. Employers and service providers should be encouraged to explore alternative measures (“reasonable accommodation”) which could assist participation.

Measures should be developed to address the practical, emotional and psychological consequences of losing the right to drive as a result of dementia.



*Appendix 1:
Zero tolerance of
restraint*

3. *Appendix 1: Zero tolerance of restraint*

**10 points for zero tolerance
for the use of restraint in persons with dementia**
*(what we have learned in the programme “Untie the Elderly and People with Dementia”
in Spain)*

1. As evidence shows, a person with a progressive cognitive impairment will be physically or chemically restrained at some point of their disorder
2. Reasons for using restraint are myths and reality has disproved them.
3. Variability in the use of restraint: why?
4. Consequences of the use of restraint on the health of patients. Mobility is necessary to preserve functional autonomy.
5. Consequences of the use of restraint for professionals and for the caring organisations.
6. The use of restraint for convenience.
7. Resurgence in the use and development of new and subtler forms of restraint.
8. The use of restraint generates ethical and legal conflicts. How much safety can be demanded?
9. Restraint-free facilities.
10. Zero tolerance is an engine of improvement. Everyone wins.

INTRODUCTION

It is the loss of judgement, the inability of people with dementia to govern themselves and behavioural symptoms, which lead us to restrain people with dementia. Regarding physical and chemical restraint, the most important factors are behaviour and anosognosia.

Zero tolerance of restraint is an attitude of professionals who care for people with dementia. It is an attitude which is spreading throughout Spain amongst professionals from different fields who do not accept the routine use of restraint.

Zero tolerance is now a common attitude in other medical areas where professionals do not accept the negative consequences of such practices in their work. It is the only approach which gives clear and sustainable results (e.g. zero tolerance of ventilator-associated pneumonia by professionals in critical care units).

As a norm, zero tolerance does not use restraint. Like every norm, it has exceptions, but only for extreme and isolated incidents.

The data which we have regarding the condition of the residents in the restraint-free facilities allows us to affirm that not using restraint is safe, just as safe or even safer than the facilities where restraint is used on a daily basis. This data also reveals that the restraint-free facilities (which have been restraint-free for months or in some cases years) have not had to make an exception for extreme cases.

Knowing the effect of the daily use of restraint, many professionals have begun to refuse to consider restraint as an option and to acquire an attitude of zero tolerance. They face an ethical conflict between the duty of care and the duty to protect and respect the person and promote their autonomy, accepting a degree of risk, as an essential part of good care.

This document is intended to facilitate the resolution of the conflict through strong arguments in favour of this attitude of rejection of the use of restraint, based on new knowledge and new experiences that invite us to change the paradigm of care.

BACKGROUND

Untie the Elderly and People with Dementia Programme



The Untie the Elderly Programme was founded in Spain in 2003. It was developed in collaboration with the Spanish Confederation of Seniors (CEOMA).

In the first years, we worked on:

- Understanding well the problem with the use of restraint in Spain and identifying the characteristics of this phenomenon.
- Investigating the prevalence of the use of restraint in Spain and the related clinical factors.
- Investigating the perception of professionals on the use of restraint.

After, we also worked on the creation of a favourable context to untie the elderly by:

- Information campaigns
- The promotion of specific laws
- Training
- Scientific activities (two international conferences on restraint in Spain)

And during this time:

We carried out fieldwork in dozens of Spanish facilities to identify the organisational and environmental factors related to the use of restraint and to find the key to avoid them.

We continued providing data on prevalence and related factors. Today we have data from 687 facilities and 29,332 residents.

Over the last three years, we have focused on establishing restraint-free facilities, which serve as examples. We have learnt that working without restraint is possible and safe and that the key to doing so is the Zero Tolerance concept. We now have 28 restraint-free facilities in Spain. The declarations contained in this document refer to the Spanish experience, with data and conclusions obtained from the work of the Programme over the last ten years and from reviewing publications on these issues from different countries.

We have always worked according to the following definitions:

Physical restraint: “Any manual method or physical or mechanical device, material, or equipment attached or adjacent to the resident’s body that the individual cannot remove easily which restricts freedom of movement or normal access to one’s body.”

Chemical restraint: “A medication that is used to control the behaviour or restrict the freedom of movement of the patient and which is not a standard treatment for the medical or psychological condition of the patient”.

TEN POINTS

1. At present we can be sure that a person with a progressive cognitive impairment will be physically or chemically restrained at some point of their disorder.

Cognitive impairment is a predictor of the use of restraint. This has been clearly identified in the literature but admitting that an illness can condemn a person to be restrained at some point of their illness can be like admitting professional failure for many professionals because it shows that they are not capable of understanding this syndrome well or of managing the symptoms in a less aggressive and damaging manner. This is the case for people with dementia especially if they reach more advanced stages.

Cognitive impairment is almost always present in people who are restrained, although it is true that resorting to restraint usually happens when cognitive impairment is combined with other conditions/symptoms such as “wandering”, serious behavioural disturbances or the risk of falls. Observation and data from the Untie Programme show that all residents restrained in Spanish facilities show some degree of cognitive impairment.

It is very difficult to obtain accurate data about the use of chemical restraint but we have data on psychotropic drug use. These medications have become the dominant approach to the management of BPSD (Behavioural and Psychological Symptoms of Dementia).

We carried out a qualitative study on the use of this medication in Spain that showed the following:

It is not always possible to find the cause, indication or objective of the use (76%).

It is not possible to evaluate the negative impact on the patient in an objective way e.g. through ADL (Activities of Daily Living).

A high frequency of PRN (when necessary) use (36%). A low frequency of dose adjustment (18%).

Chronic use (over three months, same medication and dose) (69%).

Prescribed outside the context of Care Planning (100%).

These characteristics of use are related to the purpose of restraint.

2. The reasons for using restraint are myths and reality has disproved them

The use of restraint continues to be justified today because:

1. By using it, falls could be avoided.
2. Not using restraint is sometimes unsafe for some cases of people with dementia.
3. Avoiding using restraint means an increase in the number of staff in nursing homes.
4. Families demand absolute safety for their loved ones who are incapable of caring for themselves.

People also continue to believe that physical restraint can be avoided if chemical restraint is used, and that antipsychotic medication is always useful to control the behaviour of people with dementia.

We now know that all of the above are false.

TRUTHS

Nowadays, restraining people cannot be seen as a valid means to prevent falls as it always turns into a daily use of restraint, which has worse consequences than a possible fall. The routine use of physical restraint increases the risk of falls, and most of all, it increases the risk that injuries from the falls will be more serious. Older long-term care residents receiving antipsychotic drugs are two to three times more likely to experience a fractured hip than residents not receiving this medication.

We know with certainty that the removal of restraint is safe provided that it is done properly.

We also know that physical restraint cannot be substituted by chemical restraint as the two go hand in hand. Chemical restraint is associated with a high risk of falls with serious injuries, and we know that the risk of falling is the main reason given for using physical restraint daily. Residents express twice as much agitation when they are physically restrained and this problem is linked to the use of chemical restraint.

We know that, in general, the use of antipsychotics is not a good means to control the behaviour of people with dementia, except in a few cases and for short periods of time. In general, “non-pharmacological therapies” are as useful as or more useful than medication in dealing with the “behavioural and psychological symptoms of dementia” (BPSD) and they are definitely safer. The literature on antipsychotic drug use in dementia can be summarised as follows: These drugs are harmful, they are ineffective in treating behaviour, and their use varies significantly from facility to facility according to the culture of the facility, and not the characteristics of the patients.

It is not necessary to increase the number of staff numbers in order to work without the use of restraint. Working with measures of restraint and working without them are two paradigms of care which are different from each other but which have similar workloads, although the work in each case is different. The nursing homes which have converted to restraint-free facilities in Spain did so without an increase in staff numbers.

We have also learned that family members of the patients who are well informed generally consider the removal of restraint as something positive. The facilities can offer reasonable security without using restraint, which makes a higher degree of well-being possible, and also more physical, mental and psycho-social autonomy for the people living there. Well-informed relatives tend to choose quality of life.

One of the conditions of the Spanish Untie Programme to help eliminate the use of restraint in facilities is to inform relatives of the new policy of the facility. Informative meetings are held, leaflets are published and references to the internal regulations of the facility need to be included in the contracts that are signed. In cases where restraint had been used with prior consent, the legal representative is asked to sign a document authorising the removal of the measures of restraint. Only three cases from a total of 28 restraint-free facilities, with 1566 residents were reported to the Programme of families which were against the removal of the restraint. These families maintained this position for three months before finally accepting the removal of the restraint.

3. Variability in the use of restraint: why?

The variability in the use of restraint, observed in different prevalence studies, is not explained by the condition of the residents in the facility. In the database of the Spanish Untie Programme, we have facilities with 0% prevalence of physical restraint use, and facilities with a prevalence of 67% (in extreme cases), with a similar case-mix of residents. It is easy to deduce that the determining principle of the differences in use observed is in the cultures of the organisation and hence the different attitudes in these organisations. We believe that there are contextual factors which influence (in a determining way) the

attitude of the organisation and its professionals towards this practice. We also believe that the most important of these factors are the ones that generate a perception of legal insecurity in the workers and their bosses, and a social tolerance which is common for certain types of restraint and for certain cases. Differences in the use of restraint can be observed also between countries, which suggests that there is also a social factor involved.

4. Consequences of the use of restraint on the health of the patients. Mobility is necessary to preserve functional autonomy.

There are many references which show the effects of restraint on people's health. The majority of them are linked to the consequences of inducing immobility on the person, making it impossible for the person to move, or due to lack of strength/vigour and physical exhaustion (adynamia) in the case of chemical restraint. Immobility is considered a syndrome and the effects on the person with dementia are well documented.

As well as immobility, physical restraint also causes other complications in the patient, some related to rejection and struggling and others related to the psychological effect of being restrained, with serious behavioural problems and, most of all, agitation. Medication used for restraint has serious negative secondary effects on people with dementia, especially if administered daily in combination with other medication. In behavioural terms, they can triple verbal aggressiveness in people consuming antipsychotic medication.

Data from our own Spanish research (Untie Programme) shows that 67% of patients with dementia take antipsychotic medication and that 97% of antipsychotic medication is consumed by patients with documented cognitive impairment. According to a study carried out by Dr Banerjee, it is estimated that only 20% of these prescriptions in the United Kingdom (UK) correspond to a correct treatment, the rest being considered as inappropriate use with a restrictive purpose. Dr. Banerjee highlighted the higher morbidity and mortality caused by these drugs in people with dementia.

Finally, the sum of the effects of restraint on the health of the patient leads to a substantial loss in the functional autonomy of the patient which can be irreversible. In some cases, where the patient is especially fragile, the effect of the restraint can be catastrophic.

Ultimately, restraint hampers the necessary mobility of the person to a greater or lesser degree, impeding their normal development and the preservation of their bodily functions.

Use it or lose it: true for brain and body

5. Consequences of the use of restraint for the professionals and for the caring organisations

Professionals renounce other clinical practices when they resort to the use of restraint, which means an impoverishment of their work and a serious limitation in their professional development. The “Untie Programme” in Spain reached this conclusion when we carried out studies in facilities using restraint to identify and analyse the factors which influence this. In these exhaustive interventions in the facilities (72 in total), we observed a repetitive pattern:

- The registration of falls is limited.
- The analysis of falls is insufficient and does not take into account all the factors which may help to prevent falls, especially environmental and organisational factors.
- A structure for the management of falls and the use of restraint does not exist (e.g. committees, multidisciplinary teams).
- Many behavioural symptoms of dementia are not evaluated. They are only evaluated when there is a significant impact on other residents and on the carer's work.
- Non-pharmacological therapies for the management of people with dementia and their behavioural problems “symptoms” are not used.
- Strategies for the rationalisation of the use of psychotropic medication are not applied.
- Strategies for the rationalisation of polypharmacy are not applied.
- The use of psychotropic medication and the management of behavioural problems/symptoms are not dealt with in an exhaustive way at interdisciplinary meetings. Staff decisions on the use of restraint are strongly influenced by the staff in direct contact with the patient (i.e. by the nursing assistants).
- There is an important failure in delaying the onset of incontinence in people with dementia.
- Protocols for falls and restraint are not consistently applied.
- More practical instruments for evaluating the functionality of people with dementia and their symptoms have not been widely implemented, and if they are being used, they are used badly e.g. FAST (= Functional Assessment Scale).
- No information about what the person with dementia is likely to experience is given to families in advance so that they can make decisions in advance.
- Scarce promotion of mobility, strength and muscular resistance.
- There is a poor system of detection of significant changes in the condition of the patient and “sentinel events” (i.e. which are cause for alarm), and adequate response to these events.
- The training of professionals is not adequate or suited to the real needs of the patients.
- There is poor ethical reflection on the use of restraint.

All this allows us to conclude that clinical practice on the part of the professionals in the interdisciplinary boards is of poor quality and caused by the use of restraint which does not allow professional development and the acquisition of experience.

The use of restraint can also have an impact on the emotional state of the professionals, such as anxiety, frustration and feelings of guilt. More specifically, we can say from our research that there were more cases of burnout (evaluated by the Maslach scale for health professionals) in facilities where restraint was used most.

Equally, care organisations, where the policy is to restrict their patients, reject the development of creative organisational strategies to increase the safety of their residents, and they are not aware of environmental and technical aspects which promote the safer mobility of their patients. In our research in the facilities, we observed serious deficiencies in the passive physical security, things such as free access to dangerous zones, poor lighting, a high number of obstacles in walking areas and overcrowding in certain areas. Regarding the furniture, there were few options to adapt the heights of the beds to the needs of each person, hardly any variety of seats, which was insufficient for the different characteristics of the patients.

The organisations that use restraint may suffer a greater legal insecurity and they may also face greater conflict with the families of the residents. We believe that these negative effects are due to the false perception of safety that restraint gives, with the consequent relaxation of the necessary surveillance and accompaniment that professionals should provide, and the consequent mistaken conviction of family members that by using restraint their loved ones are safer. A review of Spanish case law shows a high incidence of lawsuits for cases of negligence, lack of diligence and abandonment of care.

6. The use of restraint for convenience

The use of restraint for convenience can be defined as a use which results in the reduction of the workload and less effort for the employees in the facility, but a use which does not target the well-being of the person with dementia. The use of restraint should never cover up a deficiency, lack of professional capacity or organisational defects in the facility.

When we analyse the affirmation “more staff are needed to avoid using restraint” (a very prevalent idea in society), we deduce that there is a certain universal tolerance of restraint as it is believed we can save on human resources using this practice. All society should reflect on this. Fortunately, this affirmation is based on the myth that one cannot avoid the use of restraint without increasing the number of staff.

In studies carried out by the Spanish Untie Programme, we have found that all restraint used is used on a daily basis, and that the patterns of its use correspond to the convenience of the facility or the staff.

It is interesting that precisely when professionals try to use restraint for the shortest time possible, they show that its use is for convenience or because of organisational deficien-

cies of the facility. This is the case for restraint used only at night, for restraint used only for a short period of time every day at the same time, for that used only in one type of chair and not in another, or for that used only in some places and not in others, or which are repeated every day under the same circumstances. To show that they are not being used for convenience, they would have to explain why they are needed only in bed and not during the day, or why they are only needed at certain times of the day, and not at others, and why they are needed every day at the same time, or why they are needed only in certain places and not in others. All these uses of restraint could be avoided if timetables and the organisation of work were modified, if beds and chairs were adapted, and if the rules of the facility and its environment were changed.

Certainly, it is a false convenience because it may seem cost effective in the short term but the consequences of the daily use of restraint include more work, complications and cost to the organisation.

7. Resurgence in the use and development of new and subtler forms of restraint

There are references to this phenomenon, a resurgence in the use of restraint in facilities that have been followed for a long time after its reduction. We learned a very important lesson in our own “untying” experiences in Spain. The first 44 “interventions” were carried out with a modest objective; the objective was to reduce the prevalence but not to eradicate the use of restraint. Experience showed us that during this process of reduction, they looked for other subtler means of physical restraint, or medication with restrictive potential other than the conventional psychotropic drugs used to restrain and what is most interesting is that after months of achieving the maximum possible reduction in the use of restraint, there was a resurgence, and that after 6 months, the prevalence of restraint was similar to what existed at the beginning. At the end of 2009, we began to work with an attitude of zero tolerance in order to achieve restraint-free facilities, and at the end of 2012 we have 28 successes. We think that mentalities do not change until the facility has worked for some time without restraint, and that they do not remain free if this mental change does not happen.

A great skepticism prevails on the possibility of working without the use of restraint. SEEING IS BELIEVING. Professionals only believe it when they manage not to use restraint themselves for some time.

And so preventing the resurgence of the use of restraint is assured when the facility eradicates all restraint and continues to do so for at least 3 months or until it consolidates the necessary mental change. It is also necessary that the facility is habilitated for this, and that there are no legal threats or social pressures that could change the attitude of zero tolerance.

In order to prevent the resurgence in the use of restraint or new forms of restraint, a favorable context is necessary which is conducive to restraint-free care.

While the convenience of third parties continues to be considered acceptable and there is still pressure on professionals which generates fear and conflict in professionals in relation to possible accidents in the patients, a resurgence in the use of restraint occurs and it stimulates the development of new, subtler and masked forms of restraint.

8. The use of restraint is a practice which generates ethical and legal conflicts. How much safety can be demanded?

In Spain, the principal cause of ethical conflicts for professionals working in nursing homes is the use of restraint. There is also supporting evidence of this in studies carried out in other countries. In one wide-scale study involving 577 nursing staff into the abuse of older people, those interviewed widely agreed that the abuse in the form of physical restraint was the most frequent form of physical abuse.

On the other hand, we detected in our work in Spain that the directors of the facilities and the doctors were afraid of the possible legal consequences for them should the residents come to any harm, and we also found that there was a more hostile attitude amongst the family members of the patients in the facilities where they used restraint than in the restraint-free facilities.

The use of restraint creates a false sense of greater security

Although the staff in the nursing homes experience a tension between their duty of care and their duty to respect the human rights of the residents, the Untie Programme has established that once they see that nothing happens to the patients by removing the restraint, they feel calmer and gladly accept to work without restraint. SEEING IS BELIEVING.

Restraint-free facilities in Spain show us that the use of restraint can be avoided and that this is safe for the patients.

According to our experience, the stress experienced in removing the restraint (i.e. untying) lasts between three and six months.

Professionals who have a non-restrictive attitude ask the same contradictory question ("How much safety is safe?") as their colleagues and the relatives of the patient, and they also share the arguments which provide an answer to this question in every case of doubt. This avoids ethical conflicts and prevents lawsuits arising from the decision to avoid the use of restraint.

How much safety can be demanded?

The Programme has established a minimum safety requirement required for centres that eliminate the use of restraint. The minimum security conditions required are:

- The centre responds appropriately to avoid damage in all cases of serious and imminent threat to the life or integrity of oneself or others.

- In the centre, the incidence of hip fractures should not exceed 1.5 in 100 falls.
- In the centre, the incidence of serious head injuries (requiring transfer of the person to the hospital) should not exceed 0.5 in 100 falls.
- In the centre, people with dementia should not have a prevalence equal to or above 3% (every day for 7 days) of serious behavioural problems such as verbal abuse, physical abuse, socially inappropriate or harmful behaviour or the refusal of care.

Based on the studies of incidence and prevalence of these problems, and on the basis of our database (i.e. that of our Programme), of the facilities that are using physical restraint on a daily basis, the incidence of hip fractures is 3 to 5 in 100 falls, the incidence of serious head injuries is 1 in 100 falls, and the prevalence of serious behavioural problems is over 8%.

9 Restraint-free facilities. Prevention is better than reaction

There are no lives without restrictions and this is also the case for people with dementia, but there are nursing homes which do not apply physical or chemical restraint. These are the restraint-free facilities. In Spain there are 28 centres, verified by us, that have eliminated all use of restraint.

If in a nursing home, they do not apply a new means of restraint, apart from those already having been applied, it will be converted into a restraint-free facility in a given time. This is a strategy of prevention.

When we help a facility to become a restraint-free facility, we propose that they arm themselves with the necessary strategies to avoid applying a new means of restraint, that it would be useful for them to mark the date when they can begin to avoid using restraint completely and in the meantime, they must start a process of eliminating restraint already used in the facility. The professionals themselves, after a period of training and obtaining experience, admit that it is easier to avoid using new means of restraint than eliminating that which they have been using. Prevention rather than reaction. After a period of using restraint on a daily basis, many people lose their autonomy. Not only can this be irreversible but it can make it even more difficult to deal with them without using restraint. It is a vicious circle.

Restraint-free facilities are so (i.e. restraint-free) because the professionals and manager have adopted an attitude of zero tolerance, sometimes even going against the opinion they used to have on this issue.

We now know that maintaining a certain degree of tolerance towards the use of restraint results in failing to achieve its total elimination, although it is possible.

The facilities where we are carrying out our research are facilities which once used restraint and managed to eradicate its use completely through effort and a suitable strategy. These facilities have shown us that a change of paradigm is possible and necessary

to maintain restraint-free practice. They also show us that it can be achieved without increasing staff numbers, without conflicts with the relatives of the patient and without a big incidence of complaints or lawsuits.

We have also seen more effective formulas in achieving it that are safer than using restraint, taking as a safety indicator the incidence of fractured hips. There have been improvements in many other aspects as we will see in the following point.

10. Zero tolerance is an engine of improvement. Everyone wins

In order to acquire an attitude of zero tolerance, one must face the challenges that people with dementia pose every day with more knowledge, better strategies and more creativity. Apart from this, new experiences improve the capacity of the professionals. When they work like this for a time, they gain greater respect from others. They improve their knowledge about the prevention of falls, dementia and its BPSD, handling the environment, technical aids, non-pharmacological therapies, the management of psychotic drugs and polypharmacy. Experience is acquired by dealing with these problems without the use of restraint, and developing strategies to prevent them. As the interdisciplinary teams are improved in this respect, they become more capable of working without restraint in a safe way.

Professionals gain knowledge and experience and they also feel happier in their work (burn-out decreases). The working atmosphere in the facility is better (the loyalty of staff increases and they would now not like to go to a facility where they have to use restraint again).

The people who work in direct contact with the patients also improve their knowledge of dementia and its symptoms. In interviews carried out in the framework of the Programme, some of these professionals expressed their experience of discovering the people hidden behind the restraint, stating for example, "A lot of people began to talk and walk again". These professionals also improved the organisation of their work, which became more flexible and individualised with the aim of adapting to the peculiarities of each resident.

We also discovered that some professionals, on hearing about these facilities expressed an interest in working in them, with the idea that they could develop professionally in these restraint-free facilities without the obstacles imposed on them by having a high number of restrained patients.

It is not only the professionals who win. Families are also more satisfied (they have a more fluid and frequent contact with the professionals in the facility). The patients with dementia themselves are the ones who benefit the most, with clear indicators of improvement in their physical and mental conditions, and a progressive increase in their autonomy. The prevalence of serious behavioural symptoms decreases which leads to a better atmosphere in the facility (the patients are calmer without restraint).

Facilities improve their environmental security, which gives more mobility to the patients, something that is especially interesting for those with preserved autonomy, or who can recover.

The facility itself improves its social image as an institution. There is a system of accreditation for restraint-free facilities in Spain. Everybody knows which facilities have an accreditation as a restraint-free facility.

CONCLUSIONS

The condemnation of the use of restraint on people because of their illness should generate a reaction which gives hope to people with dementia. We call this reaction "Zero Tolerance" and it is based on prevention.

There are no lives without restrictions. This is also the case for people with dementia, but if you can avoid direct physical and chemical restraint (which is a great achievement for the respect of the person), then you have a moral duty to do so.


We now know that maintaining a certain degree of tolerance towards the use of restraint makes its elimination difficult to achieve. Restraint-free facilities are showing us that the complete eradication of this practice is possible and that exceptions are rare.

The carer should evaluate the risk associated with mobility and accept a certain degree of risk as an essential part of good care.

In general, the prolonged use of restraint usually corresponds to a use for convenience in the world of care for people with dementia and for that reason, it is the moral duty of professionals to eradicate this practice.

Zero tolerance regarding the use of restrains is a preventive attitude. It is based on the rule of not considering restraint an option. Restraint is reserved for extreme situations which generally do not occur, if an effective prevention of the reasons to restrain has been implemented. If you apply restraint in an extreme situation, it should never be continued beyond this isolated episode. The exceptions are when the restraint is used in order to save a life, or if a person's integrity is threatened in a serious and imminent way. These cases are rare in practice and the normal thing is to work without having to use restraint (we have cases in facilities in Spain where they have managed not to use restraint for more than two years).

Zero Tolerance of Restraint: A Winning Strategy. "Zero tolerance" is quickly becoming the new paradigm in restraint prevention.



*Appendix 2:
Driving from the
perspective of a
person with dementia*

4. *Appendix 2: Driving from the perspective of a person with dementia*

James McKillop describes his experience of the impact that living with dementia has had on his driving.

Once you have passed your driving test, the law assumes you are able to drive unless you are disqualified for some traffic offences, or are judged no longer able to drive safely, due to certain illnesses, dementia being one. In my case I did have driving problems such as attempting to drive down the wrong side of a dual carriageway several times. I was positioned to turn right, indicating, ready to proceed, and it was only due to oncoming drivers flashing their headlights at me, that I was prevented from making that potentially fatal manoeuvre.

When the average person hits problems, they devise ways to get round them. I was no different. When I approached roundabouts I used to circle several times, feeling more and more dizzy and take the wrong exit in panic. I took and if it was not the correct road, I would do a U turn and return to the roundabout and repeat the process until I reached the exit I wanted. My wife Maureen refused to sit in the car with me, if I was driving. She stopped me taking my young son out with me in the car. She remarked that I kept weaving from one side of the lane to the other side then back again. I couldn't seem to hold a straight line. This of course I strenuously denied. I was a perfect driver. I also started stalling the car. My clutch control was haywire. I blamed the clutch and had it replaced, then grumbled that the garage had done a poor job. I hit kerbs when turning corners, and I just couldn't fathom out what on earth was going on. I did report my driving problems to my doctor, who advised me to stick to roads I knew very well.

It all became clear when I was diagnosed with dementia. My psychiatrist advised me to stop driving. But after coming to terms with my illness and receiving medication, I felt capable of driving, now I knew what was wrong. So I persisted with applying to continue to drive. I passed a test arranged by the DVLA [*Driver and Vehicle Licensing Agency*]. I was given a licence to drive for three years and continued to drive. I had no further problems. I no longer undertook long journeys as I, like many people with dementia, lose concentration when weary, or as the day goes on.

When I applied to renew my licence I fully expected to sit another test. I heard nothing for six months and on a Christmas Eve, I received a letter from the DVLA saying they were withdrawing my licence. What a Christmas spoiler! They did tell me I could appeal. My wife was in charge of the finances and refused to give me money for an appeal. I felt this was against my human rights and I should at least have been given another test. I later found out it was my GP who had provided the report which barred me. Yet the ironic thing is that after diagnosis by a Consultant, my GP had never mentioned the word dementia to me. She had no idea that I had been driving safely, and was unaware of my capabilities.

It is a bitter blow losing your licence. Your mobility is turned upside down. Your freedom to get up and go at a moment's notice is gone. You lose your independence. You may have to rely on others to get about. You feel a nuisance if you ask and are reluctant to bother busy people. You may feel infantilised, taken about like a toddler. It can be humiliating and demoralising. If lucky, you go in their chosen time but you are at their mercy. After all these years it still rankles to be a passenger. When I sit in a car, I still "drive". I am a terrible front seat passenger and get tired on a journey, as I watch the road like a hawk. My feet get sore with driving. Why both feet? The imaginary clutch and brake! I can anticipate other driver's manoeuvres and know when they are going to turn, when not indicating. I feel I can still drive, just give me a chance.

In conclusion, the medical person who comments on a person's ability to drive, should be the person who sees and treats the person with dementia, if someone is not diagnosed until well on into the illness, they may clearly be unfit to drive and may realise it themselves. All others should be allowed to sit a test. If someone has their licence withdrawn without a test and they respond to treatment and medication, they should be allowed to sit a test, and abide by the result. I also strongly feel that in appropriate cases there should be a restricted licence available. For example, you could be restricted to say, daylight only, A or B roads, not motorways, your local town, X miles from your home, or so many hours a day.

Finally, do not expect someone to surrender their car keys without a fierce fight. If they do hand them over, feel lucky. Any suggestion to stop driving can be like a death knell. There may be bitter recriminations, making you feel guilty. How could you be so cruel and unfeeling? But remember, you have a duty of care towards them. It is heart-breaking making the right decision. You are tearing out their heart and demoralising them, but you will have them for longer, without the added worry of what grief/havoc they could cause in someone else's life. Plenty of TLC comes in handy. Understand their anguish. You are surgically removing a great part of their life. It will be a knock to their self-esteem. There can be an overwhelming sense of loss. What have I done to deserve this!

It is better to persuade them to cease driving out of love and concern for them and others, rather than have some official body wrenching your licence from you. After seven years, I am still resentful! I would love to drive again even if it was on a race track while not in use, field, forest road or a (deserted) sand/shingle beach. Research what is available to carry on life as before. Family, neighbours, friends and members of clubs may be able to offer lifts. Is there any other alternative to driving?

If someone is having driving problems and has not been diagnosed with dementia, remember other illnesses can mimic dementia. Get a proper assessment as soon as possible.





Glossary



5. Glossary

Autonomy

Autonomy means having self-determination and exercising choice. This is traditionally associated with having capacity and being able to act rationally but this hyper-cognitive approach has been challenged. It is argued that autonomy can also be expressed by people who lack capacity and cannot explain their actions rationally (see section 1.3.6).

Beneficence

Respecting the principle of beneficence involves doing what is best for someone (e.g. something which promotes their well-being). This principle is often considered together with nonmaleficence.

Biomedical principles

The most widely known and used biomedical principles are those formulated by Beauchamp and Childress (2008). These are autonomy, beneficence, nonmaleficence and justice. These principles are used in a number of domains and not solely with regard to medical issues.

Care ethics

Care ethics (or “the ethics of care”) recognises the moral significance of relationships and dependencies in human life. It focuses, not on actions, consent to actions or decisions, but rather on care relationships, which are characterised by reciprocity and based on trust as well as recognition of possible vulnerability.

Carer

The term “carer” is used when referring to informal, non-professional carers of people with dementia. Usually carers are relatives but may also be close friends or other people who take on the informal responsibility for the care of a person with dementia.

Care staff

The term “care staff” refers to professional carers who do not have medical training and skills and who provide basic nursing care and look after the everyday needs of people with dementia. This does not include the managers of care homes as they are not usually involved in the actual provision of care.

Disability

A disability is a long-term physical, mental, intellectual or sensory impairment which, in interaction with various barriers, may hinder a person’s full and effective participation in society on an equal basis with others (taken from the United Nations Convention on the Rights of Persons with Disabilities, 2006).

Ethical

The term “ethical” is used to denote something that is considered as morally right.

Ethics

Ethics is a branch of philosophy which seeks to address issues related to concepts of right and wrong.

Freedom

Freedom means being free from interference or restriction from other people, organisations or the government. Examples include being free to live in one's own home, to go to the pub, to vote, to have a relationship and not to be subjected to measures of restraint. Often having freedom equates with having rights which are respected. The terms freedom and liberty tend to be used interchangeably.

General practitioner (GP)

A doctor who practices general medicine as opposed to having specialised in a specific field of medicine. Other terms used include family doctor, family physician or generalist.

Healthcare professionals

This is a very general term used to refer to a wide range of professionals in the healthcare domain (e.g. specialists, doctors, nurses and auxiliary care staff).

Justice

Justice covers several issues such as a fair distribution of resources, respecting people's rights, respecting morally acceptable laws, balancing the needs of the individual with those of society and avoiding discrimination, which in turn means ensuring that benefits and burdens within society are equally shared. The term "equity" is often used in relation to the principle of justice.

Nonmaleficence

Respecting the principle of nonmaleficence involves not doing anything to harm somebody and taking measures to help prevent harm.

Personhood

The way that people understand and relate to each other contributes towards the acknowledgement or development and maintenance of personhood. Personhood refers to the status of being a human being with the inherent dignity and value that accompanies that state of being. Some theorists set conditions or boundaries (such as the possession of certain capacities) to determine personhood, whereas others emphasise the role of interaction with others, the uniqueness of each person and the importance of the physical body. Alzheimer Europe emphasises that people with dementia remain persons regardless of the severity or stage of dementia.

Principles

Principles are expressions of agreed values (or "rules of thumb") which can be used to guide reflection on ethical issues and subsequent behaviour in order to come to an ethically desirable outcome. They do not provide ready-made answers and cannot be blindly

applied as every situation and person is different and there are many factors to consider when trying to behave ethically in a given situation.

Proportionality

This means that the decision or action must be in keeping with the scale of the perceived problem (i.e. not taking a sledge hammer to crack a nut).

Reasonable accommodation

This is a term used in the United Nations Convention on the Rights of Persons with Disabilities which means that necessary and appropriate measures should be taken to ensure that people with disabilities are not discriminated against and can enjoy or exercise the same rights and fundamental freedoms as other members of society (see sub-section of 2.1.1 for more details).

Restraint

Restraint is the term used to describe any method, device, substance or procedure which restricts a person's freedom of movement in the private or health and social care setting, irrespective of the intent to restrain.

Subsidiarity

Subsidiarity is an organising principle according to which the least restrictive or lowest level of possible measures should be used first.

Well-being

Well-being is a subjective experience of "being well". What leads to well-being and how it is experienced will differ from one person to the next. Examples include feeling happy, contented, satisfied, safe, cared for, healthy, wealthy and successful. However, none of these examples are necessary criteria.



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