The background of the page is a solid green color. Scattered across this background are several white, five-pointed stars of varying sizes and orientations, some overlapping each other.

# Legal capacity and decision making: The ethical implications of lack of legal capacity on the lives of people with dementia





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# Preface



Dear Colleagues, Friends, Ladies and Gentlemen,

I would like to welcome the latest Alzheimer Europe Ethics Report. This report is a result of work carried out by a panel of experts coordinated by Dianne Gove. The members of this panel included

a spectrum of Alzheimer societies representatives, scientists and professionals, amongst whom ethicists, lawyers, psychiatrists, philosophers and dementia specialists, and especially a representative of the European Working Group of People with Dementia, because Alzheimer Europe values the contribution of this group in all its work.

This ethics report leads us through subtle, complex and complicated issues of legal capacity and decision making of people living with dementia, and considers the ethical implications of lack of legal capacity on their lives. As usual, the introductory part provides a general overview of the key issues, and explains frameworks that present a basis for further consideration. The issue of legal capacity and decision making of people with dementia is complex and difficult in principle, here even more so, because the task of the expert group was to consider legal capacity not only in the individual, local or national context, but also to address this problem from the European perspective. Therefore, the ethical questions concerning this topic are discussed not only from the perspective of different disciplines, professions

and stakeholders, but also drawing on the diversity of European legislation.

The report leads us through the most important topics: the exercise of legal capacity in the everyday lives of people with dementia and their families, participation in research, coercive measures, restrictions of freedom and the use of restraint etc. Also of importance, it looks at civil and political life, including the right to vote, formal relationships, making a will and other important situations that occur during the life course.

I am convinced that the readers of this report will be able to find important information about most areas that are connected to legal capacity and decision making of people with dementia. However, sometimes questions are raised and discussed in this report without necessarily providing clear guidance and conclusions and I think that this is also a very positive feature of this publication. In ethical considerations usually it is not possible to find only straightforward solutions, norms and guidance. These have to become part of different levels of legislation and standardization. The main role of ethics is to question the most important practices and procedures and to open the way to finding better solutions. I think that also in this regard this latest ethics report has fully achieved its goal.

**Iva Holmerová**  
Chair of Alzheimer Europe

# 1. Introduction

This report is about ethical issues surrounding legal capacity insofar as these relate to the lives and wellbeing of people with dementia. Having legal capacity means being considered as a subject before the law. It also means having certain rights (including human rights) and having the opportunity to exercise those rights, albeit with appropriate support if needed, that is acceptable and freely chosen. Over the years, Alzheimer Europe has explored ethical issues in relation to key topics affecting the lives and wellbeing of people with dementia such as assistive technology, restrictions of freedom, disability, inclusive research and the way that dementia is perceived and portrayed. It has also looked at different legal provisions of relevance to some of those topics (e.g. laws on mental capacity, guardianship, involuntary internment, marriage, voting, healthcare and participation in research). This report reflects on the relationship between law and ethics with regard to decision making in key areas of the lives of people with dementia. It will also touch on a wide range of topics such as disability, equity, wellbeing, respect for autonomy and dignity, human rights and quality of life.

It is generally assumed that law is morally justified. Law not only defines the obligations and rights that people have (along with any relevant exceptions), but also implicitly or explicitly claims that this established order is morally right (i.e. this is what ought or ought not happen). Failing to observe law or respect people's legal rights would in many cases not only be illegal but also unethical and immoral. It would, for example, be illegal but also immoral to marry someone against their will, to move into someone else's house without their permission, to force someone to move into a care home or to dictate to them how they should or should not spend their money. This is, amongst other things, because acting in this way would fail to respect personal autonomy, integrity, personhood and privacy, and would run counter to the principles of beneficence and non-maleficence (doing what is good for a person and not something that is harmful to them). Following the law does not, however, exempt people from the necessity to reflect on whether their behaviour is morally justified. In a recent statement, made in reaction to the shooting of an African American in Atlanta and as part of her resignation speech, the police chief stated:

► *"...I firmly believe that there is a clear distinction between what you can do and what you should do"* (BBC 2020a, 14/6).

Similarly, morality and law is not a mere duplication. As Gardner points out:

► *"Law enable[s] us to do, or to do better, what morally we already have reason to do. Yet it does not merely duplicate morality's existing content. Morality already told us what to do, but law added, by its authority, a suitable way to do it."*

► *"Often law is gappy and needs morality's help to make it less so"* (Gardner 2013, p.422).

Legislation and guidelines at national and European level may determine and provide guidance on how to protect and promote people's rights and how to behave ethically towards each other. This emphasises the importance of distinguishing between law and ethics despite the close relationship between the two. Particular attention is often paid to members of society who are potentially vulnerable (e.g. people with dementia). The following list provides examples of some of the key European and international conventions, directives, charters and codes which lay out some of the common values and principles of relevance to the issue of legal capacity in general and in relation to people with dementia:

- the Charter of Fundamental Rights of the European Union<sup>1</sup>
- The International Council of Nurses (ICN). Code of Ethics for Nurses (2012, revised version)
- the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (2006)<sup>2</sup>
- the Committee of Ministers to Member States Recommendation No. R (99) 4 on Principles concerning the Legal Protection of Incapable Adults (1999)<sup>3</sup>
- the Convention on Human Rights and Biomedicine (1997)<sup>4</sup>
- the International Covenant on Civil and Political Rights (1976)<sup>5</sup>
- the World Medical Association Declaration of Helsinki (1964)<sup>6</sup>
- the European Social Charter (1961, 1996)
- The Nuremberg Code (1947).

<sup>1</sup> <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex:12012P/TXT>

<sup>2</sup> <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html#Fulltext>

<sup>3</sup> <http://www.euromed-justice.eu/en/document/coe-1999-council-europe-rec-994-principles-concerning-legal-protection-incapable-adults>

<sup>4</sup> <https://rm.coe.int/168007cf98>

<sup>5</sup> <https://www.ohchr.org/Documents/ProfessionalInterest/ccpr.pdf>

<sup>6</sup> [https://www.who.int/bulletin/archives/79\(4\)373.pdf](https://www.who.int/bulletin/archives/79(4)373.pdf)

These and other documents provide valuable guidance which inevitably influences reflection and subsequent action related to the recognition of and respect for people's legal capacity. However, actual legislation as well as practices, attitudes and procedures within and between countries in Europe differ and are evolving at different paces and in different ways. These documents touch on ethical and legal issues but there are also considerable differences with regard to the objectives and attitudes of lawyers and philosophers. They may address the same issues and use the same terminology but sometimes mean different things and draw different conclusions. Van der Burg (2010, p.20) describes this as follows:

- *“A connected difference is that law is oriented towards a closure. Legal procedures are designed to reduce the complexity of the conflict, to restrict, neutralise, and end it. This focus on a peaceable closure is an attitude that many lawyers have internalised, whereas for ethicists it often seems the reverse. Philosophical discussions may continue endlessly, until one of the parties no longer bothers to respond, or has died. The basic attitude of many philosophers seems to be to add new complexities, hypothetical cases, and relevant dimensions. In too simple words: after one has consulted a lawyer, the problem may seem simpler because the lawyer has focused on only a few relevant aspects; after a philosopher has been consulted, the problem will only seem more complex.”*

The above differences are quite clear in discussions about ethical issues linked to legal capacity in the CRPD, which are quite central to this report. After this introduction, the report is divided into two sections. The first addresses some of the key concepts of relevance to the overall topic of legal

capacity, with a focus on ethical issues of relevance to people with dementia. The second reflects on some of the key areas where restrictions of legal capacity have an impact on the lives of people with dementia (e.g. guardianship, treatment and care, research, freedom of movement and participation in civil and political life).

This report was drafted by the ethics working group, which was set up by Alzheimer Europe in 2020 to explore legal capacity and dementia, drawing on the expertise and experience of the different members of the group. Because of the COVID-19 pandemic, the group had to operate virtually but still managed to address a broad range of issues and perspectives, and arrive at a consensus on the different positions reflected in the document. A short bio and photo of each member of the ethics working group can be found in Appendix 1.

The aims of this document are:

- to raise awareness about situations and practices surrounding legal capacity,
- to highlight grey zones and controversial issues linked to these and in relation to human rights and ethics, and
- to make recommendations to ensure that the rights and wellbeing of people with dementia are respected and promoted.

The main target audience of this report is health and social care professionals, lawyers and legal representatives (i.e. all those who may at some point may play a role in decisions related to the exercise and/or loss of legal capacity of people with dementia). A shorter report, for a broader audience, has also been prepared and can be accessed at: <https://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice>

## 2. Cross-cutting concepts and issues

### Dementia

Dementia is an umbrella term which describes the symptoms that occur when the brain is damaged as a result of one or more diseases or conditions. There are over a hundred different types of dementia, the most common ones being Alzheimer's dementia, vascular dementia and dementia with Lewy bodies. A person may actually be affected by more than one type of dementia. Dementia is a syndrome. This means that it consists of a common cluster of symptoms linked, for example, to memory, language, comprehension, reasoning and orientation. Dementia is usually a progressive or chronic condition. The symptoms tend to develop slowly but steadily over several years. Consequently, in combination with external factors, dementia makes it increasingly difficult to carry out everyday tasks. Although the prevalence of dementia is higher amongst older people, dementia is not a natural part of growing old.

Aside from legal capacity, which focuses on the right to make binding decisions, the capacity to do things and make decisions (decision-making capacity), is also important in the context of dementia.<sup>7</sup> There is not one but numerous capacities covering a range of tasks (such as making coffee, driving a car, following the thread of a conversation and doing calculations etc.) and a range of decisions. Such decisions could, for example, include what to have for dinner, where to go on holiday, whether to attend a concert, as well as decisions with more serious consequences such as whether to have an operation, how to invest or spend large sums of money and whether to get married or divorced.

People carry out tasks with varying degrees of success and skill. However, having dementia tends to make it more difficult to carry out routine activities, which used to be straightforward and taken for granted, such as cleaning, getting dressed or washing the car, as well as more complex activities such as driving or managing finances. People often devise coping strategies so they can manage relatively independently for longer. Many people with dementia at some point need some kind of assistance or care, as well as measures to support decision making. It is important that the right level of appropriate support is provided when needed so that people with dementia can maintain their independence and exercise their autonomy for as long as

possible. Choosing the kind of support needed and who should provide it are also ways to exercise autonomy.

The kind and level of support needed may fluctuate because different capacities (i.e. to do things as well as to make decisions) are dependent on the task, context and situation. This covers a wide range of factors such as the time of day, the complexity of the task or decision, levels of awareness, noise and other distractions, stress, the effects of medication and so on. The ability to successfully carry out a task, which includes making certain decisions, cannot be explained solely in terms of people's impairments or medical conditions. Practices, attitudes and the way that society is organised can also help or hinder capacities and affect the full participation of people with dementia in society.

### Disability

In keeping with the social model of disability, the impairments that people with dementia have and the interaction of these within society (e.g. lack of appropriate support and adaptations, as well as ignorance and lack of consideration) may result in disability. This means that people with dementia often do not benefit from the same rights and opportunities as other people to participate in society. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) is an international human rights treaty. It was adopted in 2006 and has been ratified by all Member States of the European Union (EU) and by the EU itself in December 2010. The EU and its Member States are therefore committed to ensuring respect for the human rights of everyone with disabilities and to achieving this through the adoption of new legislation and policies, and by reviewing existing measures. Article 1 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD 2006) states:

► *“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.”*

The early disability movement was set up by people with physical disabilities and many people still associate disability with physical impairments (as still reflected in the

<sup>7</sup> See section “About legal capacity and decision-making capacity” (p.14).



universal symbol of disability as a person in a wheelchair). It has expanded over the years to incorporate people with a more varied range of impairments and disabilities. Alzheimer Europe, for example, recently established closer ties with the European Disability Forum and emphasises that article 1 of the CRPD also applies to people with dementia.<sup>8</sup>

The provisions of the CRPD reflect the social model of disability and a human rights discourse, which seeks to ensure independence, freedom of choice, and full and active participation of people with disabilities in all areas of life and society. This may be achieved through rules, regulations and laws, as well as through carefully planned and meaningful involvement of people with disabilities in society. The PANEL principles are:

- Participation** (of rights holders),
- Accountability** (of duty holders towards rights holders),
- Non-discrimination and equality** (of duty holders towards rights holders),
- Empowerment** (of rights holders),
- Legality** (of duty holders' actions).

The European Commission has provided further guidance to using the PANEL principles in the form of the FAIR flow-chart. This consists of establishing the:

- Facts**,
- Analysing the rights at stake**,
- Identifying who is responsible for bringing about change and**
- Reviewing any action taken.**<sup>9</sup>

Not everyone with dementia considers themselves as having a disability or wants to identify with disability. Similarly, not everyone who experiences dementia has the same objectives. Positive and supportive actions, based on the principles of solidarity, justice and mutual respect should be encouraged, whilst taking care to avoid generalisations about what people want. People should not be obliged to define themselves and should not be officially labelled on the basis of disability or of particular care needs (e.g. being referred to as a 'Pflegefall' in German, which literally means a 'care case') (Deutscher Bundestag 2010). Shakespeare et al. (2017) suggest that whilst people with dementia will vary in terms of their willingness to be identified as disabled, they, like other groups in society, can still use the CRPD as a 'tool to advance their rights'. It should be noted that the term 'disabled' is often used as a political statement which suggests that people are disabled by society, rather than as a description of a personal, intrinsic characteristic. Morris (2001, p.3) states:

▶ *"We therefore use the term "disabled people" to describe what is done to us. This language politicizes our experiences and it takes the focus away from our impairments being the problem and puts the responsibility onto the society in which we live."*

The CRPD gives disabled people certain rights because the countries which have ratified the CRPD have committed to certain obligations towards disabled people.

The CRPD does not provide a list of conditions which count as disability. This is perhaps in keeping with a move away from the medical model of disability which locates disability within the person and their condition, without making a distinction between impairment and disability and without acknowledging the role of the environment in contributing towards disability. The absence of such a list may, nevertheless, sometimes make it more difficult to challenge and eventually change perceptions of what disability is amongst relevant governmental agencies and authorities. To complicate matters, in some countries there is no legislative definition of disability. This is the case in Denmark and Finland. Moreover, in some countries which do have a legislative definition of disability, such as in the Czech Republic, Estonia, Latvia and Poland, the concept of disability is narrower than in the CRPD (Council of Europe 2020). Consequently, the CRPD does not always succeed in practice in promoting the rights and wellbeing of people with dementia.

Finally, it is important to avoid looking at disability in terms of 'them' and 'us'. Disability (including that linked to dementia) is not always visible, and impairments may result in varying degrees of disability or indeed none at all. Some people with disabilities, especially resulting from impairments acquired later in life, may already have deeply ingrained negative views about disability. This may also affect their self-esteem and willingness to be defined as disabled. It has also been suggested that people with disabilities consider some disabilities more or less acceptable or desirable than others (Deal 2003).

## Discrimination

### Stigmatization

Stigmatization is a process and a complex social phenomenon which is relevant to the discussion about discrimination against potentially vulnerable groups. It involves:

- the identification and labelling of socially salient characteristics,

<sup>8</sup> See: Dementia as a disability? Implications for ethics, policy and practice. A discussion paper (Alzheimer Europe 2017).

<sup>9</sup> See the Scottish Human Rights Commission leaflet for more details: [www.scottishhumanrights.com](http://www.scottishhumanrights.com)

- negative stereotyping,
- cognitive separation (considering people with those characteristics as ‘other’ in the sense of ‘them’ not ‘us’, as mentioned above),
- devaluation/loss of social status,
- discrimination,
- and emotional reactions (Link and Phelan 2001, 2006).

The social construction of stigma is also inextricably bound to the exercise of power and to social structures (Parker and Aggleton 2003, Link and Phelan 2006, Mahajan et al. 2008 and Scambler 2009). Discrimination can occur in the absence of stigmatization but it is also an essential component of it. A particular characteristic/attribute comes to be considered as a stigma (sometimes called a mark) because of the meanings associated with it. These can change over time and differ from one social setting to another (e.g. in the case of having tattoos, being divorced, being left-handed or having an artificial limb). Some attributes are fairly stable in being considered as stigmas whereas others gradually become less socially salient. Whilst a great deal of progress has been made, people with certain disabilities and medical conditions (e.g. dementia, schizophrenia, learning disabilities and leprosy) continue to experience stigma, and hence discrimination.

In the literature on stigma, the emphasis is often on perceived difference and on a range of contributing factors such as concealability (and visibility), course/progression (how the attribute develops or worsens over time), disruptiveness, aesthetics and origin (perceived responsibility) (Jones et al. 1984). Perceived threat or ‘peril’ plays a key role in the social construction of stigma (Jones et al. 1984, Stangor and Crandall 2003) and may increase the tendency to emphasise difference (Levey and Howells 1994). Perceived threat can take several forms. It can, for example, be linked to a challenge to the established moral order or to the stability and cohesion of the dominant social group, to contagiousness or even to behaviour which risks violating personal space or physical integrity) (Hinshaw 2007).

Perceived similarity can be worrying as it may heighten people’s fears that something bad could happen to anyone, including themselves (Lerner 1980). People who have made a separation, such that they see people who have dementia as completely different to those who haven’t (including themselves), may feel protected. Stereotypes and negative images of advanced dementia (which are often generalised to dementia in general) may thus have a double function in amplifying perceived difference and thereby providing a sense of security, but also contributing towards stigma (Gove et al. 2016). The role of powerful emotions, particularly deep-seated fear, and the lack of power of certain groups in society, makes it difficult to overcome discrimination. Restrictions of legal capacity by definition involve some loss of power.

## The nature of discrimination

A common feature of various definitions of discrimination is that discrimination consists of people being treated differently on the basis of certain characteristics and that such differential treatment is in some way detrimental to them or unfair. The issues at stake usually revolve around advantages and opportunities. This can also include the opportunity or right to do things that contribute towards society, such as donating money to charities, serving on a jury, giving blood or taking part in research. There are different types of discrimination such as direct, indirect, harassment, instruction to discriminate, discrimination based on perceived disability and discrimination by association (as described by the Council of Europe 2020). Anticipated discrimination (like the threat of coercive measures or the assumption that freedom will be restricted) can be equally damaging, especially in the field of mental health and for people whose legal capacity has been restricted.

Discrimination is described in the CRPD as being a violation of the inherent dignity and worth of the human person (Preamble, paragraph 8). Scholten, Gather and Vollmann (2021) point out that the CRPD is the first human rights document that specifically refers to disability as one of the socially salient attributes that should not be considered as a justifiable grounds upon which to make a distinction, exclusion or restriction. The CRPD set out to eliminate discrimination against people with disabilities. It takes the stance that it is discriminatory to deprive people with disabilities, including those who lack decision-making capacity, of their legal capacity. According to Scholten, Gather and Vollmann (2021), a combined supported decision-making model, which may involve substitute decision making if deemed necessary, does not constitute discrimination. One reason for this is that the potential loss of legal capacity is not based on belonging to a particular group (e.g. a marginalised or socially salient group), on a diagnostic label or on an irrelevant property. Rather, it is based on an assessment to make a specific decision about a specific issue at a specific moment in time, having been provided with all possible appropriate support. Please see subsection on ‘Different approaches to support and empowerment’ (p.18) for a brief overview of some of the other approaches. For a full discussion about the concept of discrimination in relation to legal capacity in the context of the CRPD, please refer to the article by Scholten, Gather and Vollmann (2021).

## Reasonable accommodation

The justification to treat people differently sometimes is reflected in the CRPD in the concept of ‘reasonable accommodation’ which means:

- ▶ *“necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden where needed in a particular case, to ensure to persons*

*with disabilities the enjoyment or exercise on an equal basis with others all human rights and fundamental freedoms” (CRPD 2006, §5.3).*

The duty to provide reasonable accommodation applies to a wide range of stakeholders, including healthcare providers and providers of goods and services amongst others. It is a means and also an obligation to put an end to any situation of discrimination based on disability. This could, for example, involve making adjustments to buildings or buses, such as ramps and signposting, to make them accessible to everyone. It could also involve adapting procedures and services so that everyone can benefit from them and providing advice and support so that people can all enjoy not only the same opportunities but the same outcomes. It is therefore not unethical to treat people differently, even on the basis of shared characteristics, provided that it does not disadvantage certain people based solely on their membership of a socially salient group. An understanding of the difference and relationship between equality and equity is important in this context. An approach based on equality involves treating everybody in the same way without taking into account differences between people, which may be inherent, linked to circumstances or structurally determined.

Equity is therefore not about simply providing everyone with the same opportunities but about fairness and equality in outcomes. Issues related to inequity need to be addressed when striving for equal opportunities and outcomes. With regard to the image of a baseball match<sup>10</sup> (please see Figure 1 on page 10), it is not about giving everyone the same box to stand on regardless of whether they need it (image on the left of equality) but it's about giving people as many boxes as they need to be able see over the fence and watch the match that others might be able to watch without needing to stand on a box (image on the right of equity). The concept is also linked to that of solidarity. In the context of shared or supported decision making and inter/personal interactions with people with dementia, it is important to consider what reasonable accommodation would mean and what would be considered 'reasonable' as opposed to disproportionate or interfering.

## Respect for personal autonomy

### Individual autonomy

The concept of legal capacity is closely linked to that of autonomy. In Western ethics and political philosophy, autonomy is often described as “a state or condition of

self-governance, or leading one's life according to reasons, values, or desires that are authentically one's own” (Taylor 2017). Much of the current debate surrounding autonomy is linked to the work of the 18<sup>th</sup> and 19<sup>th</sup> century philosophers Immanuel Kant and John Stuart Mill, as well as to the earlier work of René Descartes and John Locke (Gómez-Virseda, de Maeseneer and Gastmans 2019). However, the term 'autonomy' dates back to ancient Greek times when it was used in connection with self-rule or sovereignty of city states. It stems from the Greek term 'autos' (meaning 'self') and 'nomos' (meaning 'rule'). The original concept of self-government in relation to a city state has been extended to that of self-government in relation to individual human beings. The opposite of autonomy is heteronomy, which means being governed by outside influences or external constraints. Autonomy is often described in terms of the ability to make individual, fully-informed and independent decisions (Gómez-Virseda et al. 2019), which renders it almost synonymous with decision-making capacity, with a focus on isolated decisions rather than decision making as an ongoing dynamic process. It is also often associated with necessary conditions and capacities for having it, such as:

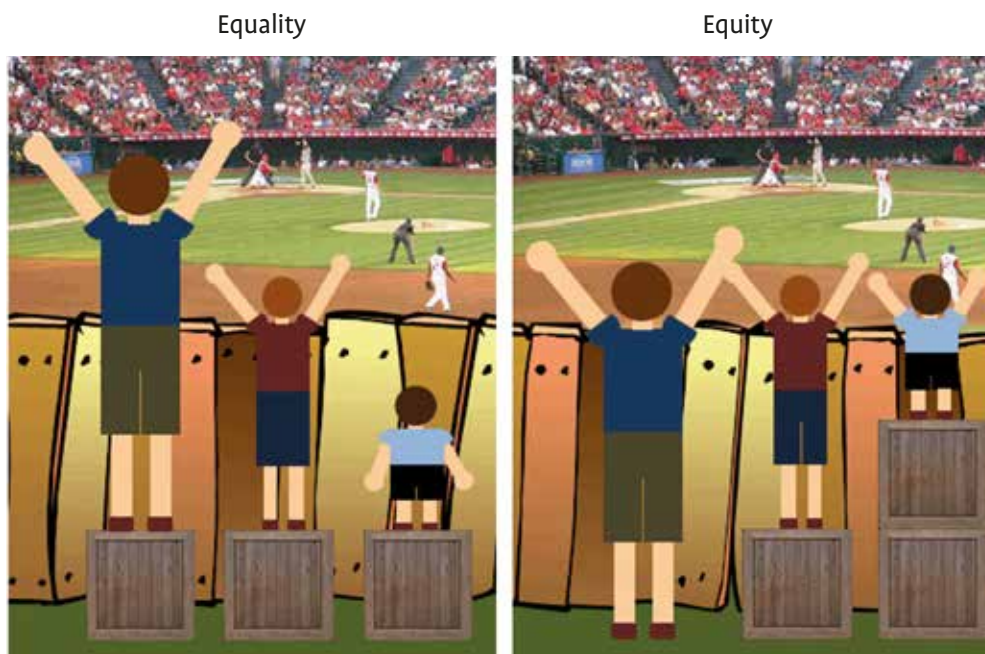
- freedom of will (not being unduly influenced or forced),
- independence (in this context, not being dependent on others to make decisions and not being restricted in the range of options available due to being dependent on others for care or support),
- self-determination (being able to take decisions and act in ways that allow people to lead the life they want to live, albeit within certain unavoidable constraints, linked to living in civilised societies),
- sense of self (decisions and acts should reflect people's sense of self - which has led to debates about critical and experiential interests<sup>11</sup>, as well as about current and past 'selves'),
- individuality (recognition that people's acts and decisions should reflect their own wishes and desires, unique character and even eccentricities).

Autonomy was referred to in the Belmont report (1978) in relation to the principle of 'respect for persons' in terms of treating people as autonomous agents and protecting those with diminished autonomy. This was further developed by Beauchamp and Childress in their influential publication on biomedical ethical principles (2001) where it was one of four broad moral principles, namely respect for autonomy, nonmaleficence, beneficence and justice. Gómez-Virseda et al. (2019) point out that discussions about autonomy are often linked to the concepts of personhood<sup>12</sup> and dignity.

<sup>10</sup> By Craig Froehle (2016).

<sup>11</sup> See Life's Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom by Ronald Dworkin (1993).

<sup>12</sup> For a more detailed discussion on the issue of personhood, please see Alzheimer Europe reports on definitions and approaches, and on disability: <https://www.alzheimer-europe.org/Ethics/Definitions-and-approaches/Other-ethical-principles/Personhood>, <https://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice/2017-Dementia-as-a-disability-Implications-for-ethics-policy-and-practice/Personhood-and-the-personal-experience-of-disability>

**Figure 1: The relationship between equality and equity**

Source: <https://medium.com/@CRA1G/the-evolution-of-an-accidental-meme-ddc4e139e0e4>

According to Hanssen (2004), the desire to act ethically sometimes results in professional carers feeling that they are not respecting a person if they do not act in accordance with that person's wishes (even if the person is unable or unwilling to make a decision, or if respecting those wishes would result in serious injury or harm). This is perhaps linked to the terminology of respect associated with the concept of autonomy (i.e. respect for persons and respect for autonomy) and/or to growing recognition that personhood ought not be considered as dependent on the possession of various capacities, but rather on merely belonging to the community of human beings.

The exercise of autonomy is usually dependent on people having certain information, as typically emphasised in debates about informed consent to treatment or to participation in research. Often, it does not give sufficient attention to key values such as justice, social responsibility (Gómez-Virseda et al 2019) and the fiduciary relationship between doctors and their patients. See also subsection on informed consent in Part 4 of this report (p.27). Hanssen (2004) describes the provisions in the Norwegian Nurses' Code of Ethics as requiring respect for the patient's right to make choices and the provision of opportunities to make independent choices, as well as adequate, individualised information to enable them to do so. For example,

determining whether or not to move into a residential care home may depend on knowledge about how good it is, whether the staff are friendly, speak one's language and are competent, how much it costs, whether friends and visitors would be able or likely to visit, what the other residents are like, how much privacy there is, what other options there are instead of going there etc. These questions need to be considered alongside other questions such as:

- Was there a real choice or was it necessary to choose between two or more unsatisfactory options (e.g. linked to structural discrimination or to socio-economic inequalities)?
- Whilst the choice may have been made freely, could there have been some form of subtle pressure influencing the decision (i.e. at the interpersonal or societal level)?
- Was the information suited to the person's level of education, literacy and understanding of the language in which it was written?
- Was appropriate support available to help the person to obtain and understand the relevance of the information for their life or situation?

Discussions about autonomy frequently focus on decision-making capacity<sup>13</sup> but justice, equity and solidarity

<sup>13</sup> See subsection on "Legal capacity in the context of the CRPD", particularly in relation to article 12.

are also linked to autonomy. People with dementia do not necessarily have the same options and the threshold for accommodation that is considered 'reasonable' may well be different to that for other groups (e.g. for people with other disabilities who are in paid employment). Consequently, the possibilities for self-governance may well be restricted to a smaller world with fewer potential roads to go down (i.e. limiting the exercise of autonomy to the choice between a rock and a hard place).

### Relational autonomy

Different people attach greater or lesser importance to different factors commonly associated with autonomy and may have a different understanding of what autonomy is. In a systematic review carried out by Gómez-Vírseda et al. (2019), individual autonomy is described as being based on a 'misconception of the individual self' (i.e. on an autonomous agent being an atomistic self, sovereign and unified, self-transparent to their individual beliefs and values and self-interested in their strategic choices). They further argue that individualistic autonomy, as portrayed in bioethics, has an ethnocentric bias and overlooks other values such as family harmony, filial piety and community fealty. Loza and Omar (2017), for example, emphasise the focus in the Arab culture on a doctor–patient–family relationship, not on a doctor–patient relationship, and point out that 20 Arab States included a reservation to article 12 of the CRPD, namely against everyone having the right to exercise legal capacity. Such oversight is problematic in today's increasingly multicultural societies.

Hanssen (2004) suggests that in Western culture, autonomy is very much focused on what Childress described as 'first order autonomy'. This stands in stark contrast to the concept of autonomy promoted in more collectivist or interdependent societies where it is common for decisions to be made collectively and for some members of society to defer decision making to others (e.g. married women to their husbands, unmarried women to their parents or brothers, or people in general to healthcare professionals). This would constitute 'second order autonomy'.

It could be questioned whether handing over decision-making power to others (e.g. to fathers, husbands or brothers) is really an autonomous decision, given that those who do so did not choose their social position within society or the cultural traditions surrounding decision making. In some contexts, as mentioned earlier, the concept of autonomy as an ethical principle and even a condition for respect for the individual is so deeply ingrained that there is a risk of putting pressure on people to take decisions that they would rather defer to others or make with others. This is

also relevant to the issue of shared and supported decision making and to the importance of respecting cultural diversity and promoting intercultural care and support. There is a need to be sensitive to cultural traditions whilst avoiding leaving the door wide open to paternalism.

There has also been increasing criticism of the emphasis on independence in relation to autonomy. Agich (2003), for example, 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).

He 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. According to Boyle (2014), people all pass through varying degrees of dependence and interdependence in their lives and are never fully independent. We all rely in some way on others. Similarly, Kittay calls for dependency to be reinstated as a central part of any human relation (2011) and for assistance to be viewed as a resource, not a limitation. Autonomy has also been described as the way that a person expresses their sense of self, in their relationships and in their values and preferences (Nuffield Council on Bioethics 2009).

In debates about legal capacity, we need to move away from the emphasis on respecting autonomy as the sole means of promoting independence. Care ethicists emphasise that autonomy is not the same as independence and that it can only be developed in relationships with others (Widdershoven and Abma 2011). Subtler approaches to autonomy empower a broader section of society in that they avoid discriminating against people who have characteristics which differ to those of the typical/hypothetical rational and independent person that lawmakers have in mind. They promote equity by insisting on the right to receive appropriate and necessary support to make decision-making possible whilst questioning the need to demonstrate decision-making capacity. They also allow for different approaches to life, accepting the valid role of emotions and relationships in decision making. We live in multicultural societies and ethnic groups do not all have the same priorities and values. People from different ethnic groups must have opportunities to make decisions which reflect their will and preferences, reflecting different priorities and values. Relational autonomy fits well with the concept of shared-decision making.<sup>14</sup> However, drawing on Herring

<sup>14</sup> See subsections on “Supported decision making” and “Shared decision making” (pp.18-19).

(2001), Mäki-Petäjä Leinonen emphasises the need to consider the nature of relationships and the level of incapacity:

- ▶ *...although beneficial relationships are an important part of people's lives, relationships and social structures can also be oppressive and destructive of autonomy. Therefore, if a person with diminishing capacity lives within a relational context where their carers de facto restrict their liberty, it is hard to see relationality as beneficial to their autonomy" (2016, p.149).*

## Paternalism

Respect for autonomy needs to be balanced with other principles, values and ethical approaches. There has been some criticism of the tendency to over-emphasise respect for autonomy in the context of healthcare and research (e.g. through the overriding emphasis on informed consent). Some scholars and healthcare professionals call for a greater focus on the principles of beneficence and non-maleficence (i.e. acting for the benefit of others and not inflicting harm), especially in the context of dementia care (Smebye, Kirkevold and Engedal 2015). We would argue against creating a hierarchy of ethical principles (i.e. against claiming, for example, that autonomy is more important than beneficence, or that beneficence is more important than justice etc.). The unique factors in every situation need to be considered. This includes the context, the people concerned and the relevance of different ethical approaches, principles and values in that situation.

Reflection on the relationship between respect for autonomy and concerns about beneficence and non-maleficence should remain part of any debate surrounding legal capacity, but needs to be accompanied by reflection about paternalism and best interests. However, there is a risk in making things too flexible that people will not know what to do. A structured framework for reflection would therefore be helpful such as, for example, the dignity-enhancing ethical framework for nursing care developed by Gastmans (2013). This has a series of components, which people are encouraged to work through. One of these is for people to do what they think and feel is 'right'. Another is to act on the decision in the knowledge that they can justify it to themselves and others and that they can communicate it to the people involved. The final step of the framework is to reflect afterwards on what happened and to consider, with hindsight, what could perhaps be learnt from the situation.

Certain legal provisions resulting from a restriction of legal capacity could be considered as being paternalistic. According to Dworkin (2020):

- ▶ *"Paternalism is the interference of a state or an individual with another person, against their will, and defended*

*or motivated by a claim that the person interfered with will be better off or protected from harm."*

A distinction has been made between soft and hard paternalism. Soft paternalism consists of listening to and trying to determine what a person's wishes are and either taking measures, attempting to persuade someone to do or not do something, or trying to guide them so that they do not make poor choices or make decisions that are likely to have negative consequences for them. Hard paternalism also has the aim of benefiting the person and/or preventing or mitigating harm but measures are imposed regardless of what people feel is best for them and of their decision-making capacity.

Dworkin summarises the key issue, with regard to soft or hard paternalism, as being whether the person (to whom the paternalistic act is directed) is acting knowledgeably and voluntarily or not. Mill argued against paternalism, describing it as interfering with a person's liberty and freedom of choice, which is dependent on having opportunities to make responsible choices and on reflective decision making, but did consider soft paternalism as sometimes being morally acceptable (see below).

These issues can be teased out through different approaches to Mill's hypothetical case of someone crossing a broken bridge. Mill suggested that preventing someone from crossing a broken bridge would be an acceptable form of soft paternalism if the person does not know that the bridge is broken, but as unacceptable if the person is informed about the condition of the bridge and then wants to cross it (but is prevented from doing so). A hard, paternalistic approach would condone preventing the person from crossing the bridge even if fully informed about the danger and still keen to take the risk. In keeping with Conly's notion of 'coercive paternalism', it would be justifiable to try to prevent the person from crossing the bridge if they lacked the ability to make a 'rational choice' and would be likely to make a poor choice. The justification given for this coercive/hard paternalism is that the person's exercise of autonomy is not sufficiently valuable to offset what would be lost if they were to decide for themselves (Devi 2013). Both forms of paternalism suggest that someone knows what is best for someone else.

Paternalism (at least hard paternalism) attributes greater value to protection from harm than to respect for personal autonomy and fails to consider the right or freedom to take risks, individual interpretations of what constitutes acceptable risk and issues related to probability (the real likelihood of harm occurring). The normalisation movement began in the 1970s and was linked to intellectual disability and deinstitutionalisation. It is relevant to the debate about paternalism as it promotes 'the dignity of risk' rather

than protection. This means promoting respect for autonomy and the right to take part in everyday life (including the right to take risks in order to do so) but also complying with the duty of care where necessary (Peisah et al. 2013).

In keeping with the 'harm principle', Mill argued that a person's freedom (and hence their right) to make decisions which involve some degree of risk should not be restricted unless it harms or puts other people in danger. This suggests that people should all be allowed to make their own decisions, even ones that are risky or do not seem to be for their own good, so long as they don't endanger others. However, Mill also emphasised that other people may be harmed by the harm that a person causes themselves, because people do not live in isolation but in relationships with other people.

Theoretically, this would radically reduce people's options as many people could claim that someone else's decision was harmful to them personally. A person may, for example, decide to forego essential treatment or pain relief and it may be extremely stressful for others to witness their suffering. Someone else might decide to give away property to a casual acquaintance or leave millions to their cat, which their children or partner would otherwise have inherited (i.e. causing great sadness, disappointment and depriving them of financial means/stability). In some countries, people are

considered as having the legal and moral right to behave in this way, but if actions should, ethically speaking, not harm others, it logically follows that most decisions should be made in group consultation. Indeed, in some countries and communities, decision-making focuses on the family unit or the community rather than the individual, but this is not the cultural norm of the majority ethnic communities in Europe. Also, many people with dementia in Europe live alone and have no wider family unit or community to support them. Ethical decision making, especially in the context of shared decision making, is nevertheless moving in the direction of involving members of a person's entourage in the decision-making process.

For people with dementia, there is always a risk of pervasive paternalism based on assumptions that they do not understand the issues at stake (e.g. due to stereotypes that because of their cognitive impairments they are unable to understand or remember the information provided or to assess risks), that other people are responsible for their wellbeing (e.g. due to blanket labelling of people with dementia as vulnerable) and that other people's peace of mind (i.e. their wellbeing) justifies restrictions. Box 1 below provides a real-life example of a situation involving concerns for the wellbeing of a person with dementia who is able to assess certain risks and wishes to take those risks.

### Box 1: Point for reflection

Hilary, a lady with dementia regularly walked her dog, Tilly, in a nearby forest. Her husband was concerned about her getting lost and constantly reminded her to at least take her mobile phone with her. She often went out without it either because she forgot or because she thought he was exaggerating. One day, she tripped up and broke her ankle. There was no one around and she lay there for several hours until someone passed by and got help. She continued to go out walking in the forest after this incident because that's what made her life meaningful (i.e. feeling needed and nurturing the relationship with her dog, getting fresh air, meeting people and keeping physically fit). She was fully aware that one day she might get lost or have another accident but considered this a risk worth taking, and vowed to always take her phone with her.

#### Questions:

- Was Hilary's husband right in trying to insist on her taking her mobile phone with her?
- Should he have perhaps also tried to persuade her not to go out alone?
- Should other more restrictive measures have been taken before or after the accident?
- Were the concerns that Hilary's husband had about her safety (which can be linked to her wellbeing as well as his peace of mind) sufficient to override respect for her autonomy?
- How would you justify your responses to the above questions if you were asked?

## 3. About legal capacity and decision-making capacity

### Rights and abilities

So far, we have been looking at issues related to autonomy, independence and decision-making capacity. We now turn to the issue of legal capacity and its relevance to decision making by and for people with dementia. 'Legal capacity' is the term used to refer to the right to make decisions for oneself, within the constraints of the law, which must then be recognised as being legal and hence respected (Devi 2013). Having legal capacity means having the right to make choices about everyday matters such as buying clothes, going on holiday, whether or not to smoke or drink alcohol and having certain hobbies and friends. It also means having the right to make choices about things with more serious consequences such as getting married, buying a house, moving into a care home or having a risky operation.

People don't always have the opportunity to exercise their legal capacity (or their 'legal capacity to act'). A common reason for this is that they are not considered as having the ability to make a decision, which is known as lack of decision-making capacity (i.e. they are considered unable to understand, retain and weigh up information that is relevant to the decision and the implications for themselves, and to communicate their decision). It is generally accepted that making an unwise or foolish decision does not necessarily mean that a person lacks decision-making capacity. People often make decisions based on their emotions rather than on rational reasoning but it is probable that people with dementia are given less leeway in this respect. Mäki-Petäjä-Leinonen calls for reflection on:

- ▶ *"how much rationality is to be expected in decision making of a person with dementia (competent or not) when it is well known that even decisions made by healthy people are not always based on rational reasoning but merely on emotions"* (2016, p.151).

The functional approach to legal capacity (see below) argues that the level of a person's decision-making capacity determines whether they are considered as having legal capacity. The CRPD (see next subsection), on the other hand, argues that people should not need to have decision-making capacity to be considered as having legal capacity. This is a significant difference of opinion with considerable implications for the rights and wellbeing of people with dementia. We will come back to this debate at several points in this report. The fact that both concepts share the word 'capacity',

and that sometimes 'capacity' is used on its own, can sometimes lead to confusion.

There are several different approaches to conceptualising legal capacity insofar as it relates to conditions for its withdrawal and often, this is linked in some way to the ability to do things and/or make decisions:

- The 'status approach' equates a medical condition or impairment with decision-making capacity and considers this sufficient grounds to revoke legal capacity, regardless of a person's actual capacities. It reflects the medical model of disability and makes assumptions based on stereotypes.
- The 'outcome approach' focuses on the reasonableness of decisions that are made, whereby a decision that others consider unreasonable (a refusal of treatment considered by others as being essential would be a typical example) and might lead to the person's capacity being revoked. It suggests that there are 'right' and 'wrong' decisions and denies people the right to individuality and to live their lives according to cultural, social, philosophical, political and religious beliefs and values which differ from those of the majority population. It denies people the right to make mistakes and take risks.
- The 'functional approach' makes legal capacity dependent on actual decision-making capacity. This approach means that a person needs to demonstrate that they can make an informed decision on their own. This would include, for example, being able to understand the nature and potential consequences of a particular decision. Gurbai argues that if mental capacity assessments were to be justifiably used to determine legal capacity, they would have to be applied to people with and without disabilities and that this does not happen, which is why it is discriminatory (Craigie et al. 2019).
- The 'sliding scale approach', which is one version of the functional approach, provides a system of legal protection whereby a person is permitted to make certain decisions, either alone or with support, whereas others have to be made by a legally appointed representative. Some decisions are considered as requiring higher levels of ability than others (e.g. decisions with life or death consequences versus decisions with more trivial potential consequences). The threshold for functional decision-making capacity is linked to the level of risk associated with a particular decision.



Scholten et al. (2021) argue that the status approach and the version of the outcome approach most likely to be used in liberal democracies discriminate against people with dementia, whereas the functional approach, if employed correctly and when combined with supported decision-making, does not. All approaches still make it possible for a person to lose legal capacity and for decision-making power to be handed over to other people. Nilsson (2012) suggests that an analysis of a person's decision-making capacity (like in the functional approach) should only be used to determine the level and type of support needed and not as a yardstick by which to withdraw legal capacity. Scholten and Gather (2018), on the other hand, contend that an assessment of decision-making capacity should serve not only to determine the level and type of support needed but also to determine whether the support provided suffices to enable people to make their own decisions

The European Union Agency for Fundamental Rights (FRA 2013) distinguishes between formal and informal restrictions of legal capacity. Formal and informal restrictions of legal capacity result in the loss of the right to make decisions recognised by law. Unlike the former, informal restrictions are not based on a legal or even administrative process but on assumptions, paternalistic attitudes, ignorance and institutional procedures. Whatever the nature of the restriction, any loss of the right to make decisions can have a considerable impact on people's lives and wellbeing. Being formally and publicly declared as having no or limited legal capacity<sup>15</sup> may have a devastating psychological, emotional and practical impact, affecting self-esteem, constituting an affront to a person's dignity and affecting their personal relationships with other people and their standing in the community. It has been suggested that depriving a person of their legal capacity amounts to considering them as a non-person. Legal capacity is therefore not just a legal matter. Legal capacity and decision-making capacity are interrelated and have social and ethical implications.

## Legal capacity in the context of the Convention on the Rights of Persons with Disabilities

Article 12 of the Convention on the Rights of Persons with Disabilities (CRPD) states that everyone, irrespective of disability, has the right to be considered as a person before the law in all aspects of life, that their decisions must be legally recognised and that appropriate measures must be taken to provide them with access to the support that they may need to exercise their legal capacity.

General comment No. 1 (2014), published by the Committee on the Rights of Persons with Disabilities in connection with the CRPD, affirms that all people with disabilities have full legal capacity and that:

- ▶ *“the right to equal recognition before the law implies that legal capacity is a universal attribute inherent in all persons by virtue of their humanity and must be upheld for persons with disabilities on an equal basis with others” and*
- ▶ *“Article 12 of the Convention on the Rights of Persons with Disabilities, however, makes it clear that “unsoundness of mind” and other discriminatory labels are not legitimate reasons for the denial of legal capacity (both legal standing and legal agency)” (Committee of the CRPD, 2014, p.3).*

The Committee further claims that the denial of legal capacity to people with disabilities has led to many being deprived of certain fundamental rights. Kanter (in Craigie et al. 2019) goes one step further and argues that the right to support (in relation to the new right of universal legal capacity) has become a new human right. Whilst legal capacity is described as a universal human attribute (perhaps along the same lines as dignity), this does not mean that it cannot be taken away. Even within the CRPD and the General Comment of the Committee of the CRPD, it is stated that this can happen (e.g. in case of bankruptcy or criminal conviction) but must be applicable to everyone and not based on personal traits such as “gender, race, or disability, or have the purpose or effect of treating the person differently”.

The CRPD does not actually define legal capacity and this may have serious consequences for the very people whose legal capacity the CRPD and associated measures are intended to promote and protect. Furthermore, it has raised some controversy about whether it should be interpreted as meaning that everyone can be supported to make their own decisions (which many would argue is simply not feasible) and that substitute decision making should never occur.

In the Handbook for Parliamentarians on the CRPD,<sup>16</sup> there seems to be an indication of the need to have the capacity to understand information, appreciate consequences, act voluntarily and communicate a decision independently. It is stated that such criteria for legal capacity do not need to be proven if a person simply demonstrates trust in a designated supporter. Therefore, whilst everyone is assumed to have legal capacity, the exercise of legal capacity still seems to be dependent on decision-making capacity. People who

<sup>15</sup> An example of this is the German term 'entmündigt'.

<sup>16</sup> 2006, Ch. 6, cited by Parker 2016.

with all possible support cannot make a decision can use the supporter as a substitute, not as a substitute decision maker (i.e. typically defined as a person who takes a decision on someone else's behalf) but as a substitute possessor of decision-making capacity, by demonstrating trust. The supporter would effectively then take a decision on that person's behalf (classed as 'total support'). This would not be considered as substitute decision making but as the person exercising legal capacity by arranging for someone to act on their behalf. It is unclear to what extent and on the basis of which criteria a demonstration of 'trust' in a supporter would be considered sufficient for such a decision (which would then be considered as constituting the exercise of legal capacity of the supported person). Assumptions about trust could leave people open to abuse.

The CRPD implies that people may not only require support to exercise their legal capacity but that such support might need to be total. Article 28 of General Comment No. 1 (Committee of the CRPD 2014) clearly states:

► *“The development of supported decision-making systems in parallel with the maintenance of substitute decision-making regimes is not sufficient to comply with article 12 of the Convention.”*

In accepting the possible need for 100%/total support whilst at the same time stating that any kind of substitute decision making is unacceptable, the CRPD makes it clear that support, irrespective of the level needed, does not constitute substitute decision making. However, the suggestion that some people may need total support seems to contradict the assumption that everyone with sufficient support can make their own decisions.

Some ardent defenders of a rigid interpretation of article 12 of the CRPD argue that there may be extreme cases where a tiny percentage of decisions needs to be made and where a supporter would not be in any position to determine what the person would have wanted, but that a model of legal capacity should not be based entirely on such cases.<sup>17</sup> Rather, it should be sufficiently flexible to accommodate them (Flynn and Arstein-Kerslake 2014). They do not, however, call for every wish and preference to be respected in case of danger, and condone over-riding wishes (in the context of the duty of care) but insist that this still amounts to respecting a person's will and preference.<sup>18</sup>

According to Scholten and Gather (2018), article 12 does seem to call for an absolute ban on denying legal capacity and for all regimes of substitute decision making to be abolished and replaced by supported decision making. They elaborate several adverse consequences linked to the pursuit of these goals for people with mental disabilities:

- Insisting that people know what is best for them and are therefore best placed to make decisions overlooks cases where people (e.g. with seriously impaired decision-making capacity) do not necessarily know what is best for them (i.e. in keeping with their own values and priorities) and/or which decision will result in what they feel is best for them.
- Supported decision making emphasises the provision of support but there is little recognition of the risk of supporters being biased and either deliberately or unconsciously projecting their own interests onto the person whom they are supporting. It may be difficult for third parties to challenge decisions made because the supported person retains legal capacity and has therefore made the decision themselves. Teasing out possible undue influence is likely to be more difficult than challenging a decision made on someone else's behalf.
- Linked to the above, the person who makes the decision is entirely responsible for any consequences resulting from the decision made. Supporters may have considerably influenced that decision but it would be difficult to trace the exact nature, extent and possible underlying motives of such support, and to hold them accountable for the decision. Collective responsibility is hard to determine.
- Support for decision making requires time, money and effort so it is important to decide on conditions for its provision. It is stated in the CRPD that support to exercise legal capacity should not be based on mental capacity assessments but on non-discriminatory indicators. Scholten and Gather question what these might be other than decision-making capacity.
- Advance care planning is inextricably linked to the notion of decision-making capacity. Advance directives, for example, come into force when a person is declared as lacking decision-making capacity and hence no longer being considered as having legal capacity.

<sup>17</sup> For more on this topic, please see subsections on “Total support and substitute decision making - how to decide” (p.20).

<sup>18</sup> Same as above.

## Current legislation in the light of the CRPD

Although the CRPD, as mentioned earlier, has been ratified by all member states of the European Union, some measures of legal protection currently involve and are dependent on the restriction or withdrawal of a person's legal capacity, resulting in people no longer being allowed to make certain decisions about their lives. Nilsson (2012) suggests that the bulk of European legal capacity systems is outdated and that there is a need for law reform based on the assumption that everybody enjoys legal capacity, with a move away from a focus on deficiencies. Many people in Europe continue to be deprived of their legal capacity and placed under measures of plenary or partial guardianship (Nilsson 2012). Some laws still reflect a paternalistic approach reflecting a perception of the need to protect individuals and society from harm, which may partly reflect stereotypes about people with mental health conditions being dangerous and violent (Pathare and Shields 2012). Certain conditions, such as schizophrenia, tend to be more associated with danger to others through violence (Reavley, Jorm and Morgan 2016),<sup>19</sup> whereas others, such as dementia, tend to be more associated with unintentional harm to self and others (Crisp 2005, Werner 2005). A common response to each has been to limit people's legal capacity and to restrict various freedoms.

With regard to the imprecise and sometimes misleading use of language in the CRPD and in relation to legal and decision-making capacity in general, Gardner states:

► *“Indeterminacies of language and intention on the part of lawmakers, moreover, can afflict law in such a way as to frustrate its role as a filler of moral gaps”* (2010, p.423).

The CRPD is not a law but its provisions are legally binding for the countries which have ratified it. It therefore has great potential but the ambiguity of terminology and concepts in it may impact on its ability to improve the lives and wellbeing of the very people it targets. Such ambiguity was reportedly intentional, serving as a means to achieve consensus, but it may be detrimental to people with disabilities in that it allows for diametrically opposed interpretations (Pearl 2013).

The way that article 12 of the CRPD is interpreted will, according to Pathare and Shields (2012), determine future practices and legislation. They describe the key problem as not being in understanding the ideals of article 12 but in truly shifting from substitute decision-making to a more supportive mode. Difficulties of implementation have also been linked

to a risk of the provisions in article 12 being reduced to mere rhetoric (Pearl 2013) and to substitute decision making under a new name (Nilsson 2012). However, different patient and interest groups campaigning for law reform are also driven by different interpretations of article 12 of the CRPD and different interests and values of the groups they represent. The World Network of Users and Survivors of Psychiatry, for example, have a strict interpretation based on a complete refusal of substitute decision making. Some disability organisations interpret it as permitting guardianship measures subject to certain safeguards as a last resort (Pearl 2013), which is the approach supported by the authors of this report.

The model implicitly proposed in article 12 of the CRPD is based on the need to assess what kind and level of support is needed rather than whether a person has decision-making capacity and should have a substitute decision maker appointed (Devi 2013). Whilst governments in Europe are obliged to bring their legislation into line with the CRPD and to replace substitute decision making, based on the principle of best interests, with the more inclusive supported decision-making approach, there remains a considerable disconnect between the CRPD and national legislation.

The recent Assisted Decision-Making (Capacity) Act 2015 of the Republic of Ireland, for example, has a clear structured approach to 'assisted decision-making' which includes the appointment of a decision-making assistant and/or co-decision maker, as well as provisions for advance healthcare directives. It does not abolish guardianship as it allows for a decision-making representative to make one or more decisions on a person's behalf. However, a co-decision maker must be

► *“a relative or friend of the appointer who has had such personal contact with the appointer over such period of time that a relationship of trust exists between them”* (Part 4, 17, 2a).

This means that people who live alone or do not have a relative or friend fitting this criterion would be more likely to be deprived of their legal capacity. Nevertheless, this act, which replaced the Lunacy Act of 1871 and abolished the use of terms such as 'lunatic' and 'idiot', has been hailed as marking a historic point in the fight for equality.<sup>20</sup>

Irrespective of how article 12 of the CRPD is interpreted, it could be argued that the CRPD has been useful in reinforcing the gradual transition away from approaches based solely on best interests and substitute decision making to others

<sup>19</sup> Note: This is a matter of perceptions often fuelled by the media. Several mental health organisations refer to research which suggests that alcohol and drug use is a more reliable predictor of violent behaviour than is mental disorder and that the vast majority of violent acts are committed by people who do not have a mental disorder.

<sup>20</sup> Labour Senator Mary Moran quoted in “thejournal.ie” – 17/12/2015.

based on shared and, more specifically, supported decision making, both of which are inclusive approaches to decision making. This is reflected in recent changes in legislation related to legal capacity, in favour of approaches which require the involvement of people lacking decision-making capacity in the decision-making process and/or provide the necessary support to enable them to make a decision.

## Different approaches to support and empowerment

The move away from the concept of substitute decision making and of acting in other people's 'best interests' has been perceived as a challenge to the deeply entrenched paternalism. This has been particularly noticeable in the context of guardianship measures, as well as in the context of healthcare and involvement in research, where the concepts of shared and supported decision making are increasingly common. Indeed, it is now widely accepted that there is a moral imperative to involve people who lack decision-making capacity in decision making concerning their lives. It reflects respect for human rights and may help reduce unnecessary treatment and improve outcomes. There is evidence to suggest that people with dementia do not receive the same level of treatment as people without dementia, even when they have a higher clinical need,<sup>21</sup> suggesting structural discrimination and the need for possible support to ensure respect for their rights.

### Supported decision making

Recognition of legal capacity in different domains (e.g. consent to treatment or moving into residential care) has long been dependent on an evaluation of decision-making capacity and other capacities, such as the capacity to live independently etc. Such evaluations have typically sought to ascertain whether a person is able to provide informed consent (i.e. whether a person is able to understand relevant information, apply it to their own life, decide freely/voluntarily and communicate their decision by whatever means available or possible for them). This could include, for example, whether a treatment would be risky, what the possible alternatives might be, what kind of side effects there might be and how it might affect the person's prognosis and everyday life.

The concept of supported decision making is about providing the necessary support for someone to make a decision whereby that person retains their legal capacity, even though they would not have been considered capable

of deciding in the absence of that support. The person or people providing the support are not necessarily relatives but could be anyone whom the person trusts. This support might, for example, involve providing information, explaining issues, describing different possible consequences of various options or helping the person to communicate the decision.

Various decision aids have been developed to facilitate the process of shared and supported decision making. One Scotland (Scottish Government), for example, has produced guidelines on supported decision making for people with dementia. This covers the provision of relevant information, facilitating communication, various aids (including documents, websites, DVDs and devices), choosing the best time and place and involving other people. The National Institute for Health and Care Excellence (NICE) has a range of decision aids including one on antipsychotic medicines for treating agitation, aggression and distress in people living with dementia, which is described as consisting of "information to help people living with dementia, their family members and carers and their healthcare professionals discuss the options". This contains a non-technical summary of the different options, what NICE recommends, how people are likely to benefit, possible side-effects, other things to think about and visual representations of the risk of stroke and death.<sup>22</sup>

Support might also include the supporter actually communicating the decision but, in such cases, the supported person would still be considered as having legal capacity. The important point is that the supporter or supporters must advise and act according to the person's will and preferences, in keeping with the person's identity and respecting the right to take certain risks and to make decisions that other people might consider wrong.

As mentioned earlier, some people interpret the CRPD as implying that if supported, everyone or virtually everyone can make their own decisions (i.e. has decision-making capacity) and that supported decision making can replace substitute decision making (Parker 2016). Supported decision making is thus presented as the practical means and justification for the claim that everyone has legal capacity. However, it remains unclear what 'decision-making capacity' means, whether it is essential to have it (because all people have legal capacity according to the CRPD) and if it isn't, what the justification is for providing necessary support. Clarification would also be needed on where the law stands in this case on issues such as consent to treatment, the legality of testaments and people's right to decide to

<sup>21</sup> One example is the under treatment of osteoporosis in people with dementia, even though osteoporotic fractures are common amongst people with dementia (see Haasum et al. 2012).

<sup>22</sup> <https://www.nice.org.uk/guidance/ng97/resources/antipsychotic-medicines-for-treating-agitation-aggression-and-distress-in-people-living-with-dementia-patient-decision-aid-pdf-4852697005>

continue living at home regardless of any danger they may pose to themselves or others.

If supported decision making is not linked to an evaluation of the capacity to make a decision (i.e. under the CRPD), it is unclear at what point or how much support should be provided, but also how decision making is conceptualised. As decisions always involve at least two options, is it sufficient to indicate which one it will be or is some level of understanding nevertheless necessary of the difference between and implications of each option? There must be some level of understanding as opposed to arbitrarily selecting option A or option B. If so, then as Parker (2016) suggests, decision making must involve the fundamental ability to make choices or as Smith and Sullivan (2012, p.33) describe it “the ability to evaluate options and recall having made a choice”.

### Shared decision making

Shared decision making is one form of support that recognises the validity of the experience, views and preferences of the person directly concerned by a particular decision (in this case the person with dementia) but also that people live and move within networks of relations, and challenges paternalistic attitudes and practices. The concept of shared decision is in keeping with the concept of relational autonomy. Gómez-Vírveda et al. (2019) suggest that the influence of other people in the decision-making process enhances rather than impedes autonomy, and should therefore be actively promoted. They point out that relatives and health care professionals can promote decision-making capacity by presenting different options, providing emotional support, removing social barriers and bridging gaps between the person making the decision and the social environment.

Shared decision making should be seen as health and social care professionals and patients each laying all their cards on the table and then working together to reach consensus on the preferred treatment plan (Peisah et al. 2013). Peisah and colleagues emphasise the role of assent in shared decision making (e.g. in cases where people are unwilling or unable to play a more active role in the decision-making process). The exercise of power and influence (presumably on the part of the health and social care professionals) is perceived in terms of best serving patients’ needs. Some see it as a means to redress the imbalance created by transferral of the locus of authority from doctors to patients, which resulted from legitimate societal demands to promote patients’ rights but which some consider unhelpful (Truog 2012). Truog (2012) further emphasises that doctors are experts in facts and that such knowledge cannot hold sway over questions of values and preferences, hence the need for a collaborative approach between doctors and patients.

▶ *“This division of labour reflects a recognition of the naturalistic fallacy, the erroneous notion that one can derive ethical conclusions from scientific facts; in truth, an “ought” cannot be deduced from an “is” (2012, p. 581) .*

A collaborative approach to decision making extends beyond mere assent (whereby patients come to identify with a decision and make it their own) to one which gives greater room for patients to determine different levels of participation and to engage in a more equal exchange in which they provide information about their values, goals and non-medical factors which make life meaningful to them and contribute towards their identity. The collaborative approach is broader, involving a wider range of people, not only health and social care professionals but also supporters, assistants and relatives etc. in the context of a care plan rather than isolated decisions. It is not clear, however, how this is coordinated.

Any influence should not take the form of pressure and influence should not be ‘undue’ (i.e. to a level that is more than is necessary, acceptable or reasonable). On the other hand, an over-emphasis on avoiding undue influence and the exercise of power by doctors may lead to a kind of mandatory autonomy, lack of advice and lack of adequate support for people making difficult medical decisions (Peisah et al. 2013). This would involve doctors limiting themselves to the provision of facts and different options but withholding their own experience and recommendations.<sup>23</sup>

Shared decision making is a means to promote autonomy, especially within the context of real-life situations of interdependency (Peisah et al. 2013). It is a more positive approach to autonomy, which is much more than simply having a right to self-governance or a right to be left alone (Agich 2003). Widdershoven and Abma describe autonomy, in keeping with a care ethics approach, not as self-determination without the interference of others, but as “the ability to direct and shape one’s own life based on and in relationships with others” (2011, p.27).

For many people with dementia, participating or sharing in the decision-making process is as important as, if not more important than, making the actual decision (Daly, Bunn and Goodman 2018). However, there are a few potential barriers to effective shared decision making such as not feeling sufficiently informed or supported, fears about the ability to engage in shared decision making or of being considered a difficult patient, the impact of cultural factors linked to help-seeking on willingness to share decision making and having no family or friends to involve (Pathare and Shields 2012). Moreover, some people may have relatives but not necessarily wish to involve them. In some cases, relatives

<sup>23</sup> See subsection on “Ethical persuasion and influence in the context of shared or supported decision making (p.20).

might take advantage of people with dementia under the guise of supporting them.

### Ethical persuasion and influence in the context of shared or supported decision making

Appropriate persuasion and influence may be ethically justifiable in the context of shared and supported decision making. When healthcare professionals decide which information to give patients and how to explain or frame key options, they are inevitably also influencing the decisions that patients and their families make. Dubov (2015) suggests that they should assume responsibility for this and use it constructively to help their patients to reach a solution that from a medical perspective makes most sense and from a personal perspective corresponds to patients' values and long-term goals. Doctors are often best placed to know what the options are and which ones would be best for their patients, provided that they know their patients well and understand their values.

Doctors need to find out about their patients' values so as to be able to match those values with the medical facts relevant to each patient's situation. They also need to be able to recognise, validate and respond appropriately to people's emotions. Emotions are considered as being connected to beliefs in the sense that people fear something (e.g. grizzly bears, taking exams or losing their jobs) because of associated beliefs (e.g. being killed, being labelled a failure or ending up homeless). Often, emotions are directed at people because of reasons or beliefs (e.g. feeling anger towards someone or disappointment with someone), although the cognitive aspect of emotions may be conscious or unconscious (Dubov 2015). They are not just bodily reactions. People with dementia, who have difficulties with abstract thought, may sometimes have limited awareness of the possible reasons for their emotions or be able to explain them. The emotions may nevertheless be a way for doctors to reach out and try to understand what is important to them, and to use this to provide decision-making support.

When done in the right manner (i.e. as a collaborative/shared exercise with patients and their families), Dubov claims that the careful choice and framing of the information provided and taking into consideration people's emotions would not constitute paternalism, manipulation, coercion or deception, and can be a positive tool in medical communication. In the context of possible restraint or involuntary placement (see section 4), the issue is more complex because there is a pending threat of coercive measures being applied if the 'right' decision is not made.

### Total support and substitute decision making – how to decide

In addition to the obvious example of a person who is in a coma, many people with extremely advanced dementia (who often have difficulties with verbal communication) or in a state of delirium lack decision-making capacity for many decisions. Scott Kim describes the justification for substitute decision making as follows:

► *“The best reason (and the only reason) why we sometimes need to make decisions for others – why we cannot jettison the concept of mental capacity altogether – is that it is just a basic fact that some people cannot make decisions for themselves in any commonly accepted sense of the word ‘decision’” (In Craigie et al. 2019, p.164).*

Given improvements in healthcare, there are a lot of people living with advanced dementia. This does not represent a tiny percentage of decisions that need to be made for which it is extremely difficult, and sometimes impossible, to determine people's wishes. It is therefore not helpful or even ethical to promote a concept (such as everyone having legal capacity irrespective of the ability to make a decision) which only works well or makes sense in relation to the majority. It leaves the door wide open to abuse and discrimination. If the needs and the situation of this subgroup of the population were properly addressed, without having to twist or distort the concept to make it work, their legal capacity could be better respected and promoted.

Moreover, Parker (2016, p.387) asks, “what exactly does a requirement for support in decision-making amount to, particularly in relation to people who cannot understand relevant information, appreciate consequences, act voluntarily or communicate decisions?” People may find themselves faced with unrealistic expectations if it is assumed that they can be supported but support is not available or appropriate. People from minority ethnic groups, for example, who do not have a good command of the national language, are not known to the people charged with their support and have no family, would in many cases lack culturally appropriate support.

In the context of total support, which critics might argue amounts to substitute decision making, the CRPD calls for determinations of people's best interests to be replaced by determinations of 'will and preferences'. Where it is not possible to know this/these, a 'best interpretation of will and preferences' is proposed so as to ensure that people with disabilities enjoy the right to legal capacity on an equal basis with others (Committee of CRPD 2014, p. 5).

It is problematic, however, when there is no information available at all about a person's will and preferences, and also when the person in question did not provide any indication of trust in a supporter. Various solutions have been proposed such as the observation of people 'in a friendly manner' over a period of time, paying attention to their gestures and as far as possible involving them in decision making through activities which enable the exploration of their likes and dislikes (Devi 2103). Provided that people are able to communicate in some way, even if not in the conventional way, this might help guide supporters but it is doubtful whether such an approach would be feasible in all situations (e.g. when supporters have been appointed by a court, are not familiar with the person concerned and have many people to support within a limited period of time).

Flynn and Arstein-Kerslake (2014) describe the role of facilitators (in the context of total support) as being to imagine what a person's will and preferences would be, but one could ask whether this is realistic. In some cases, the only knowledge one has of a person is certain characteristics such as age, gender and diagnosis, and perhaps some visible signs which might (rightly or wrongly) suggest ethnicity, religious beliefs and socio-economic background. Any assumption of will and preferences can therefore only be based on stereotypes and personal bias, and risks reflecting and perpetuating prejudice and discrimination. In some cases, it could be claimed that appropriate and adequate support was provided and that the person was properly involved in the decision-making process. However, this is, after all, a matter of opinion. In some cases, such claims could hide an abuse of people's rights and constitute subtle coercion.

One approach proposed is to look for subtle signs in a person's behaviour and another is through a narrative construction of personal identity, which involves other people finding an answer to the question "who is the disabled person?" – based on their life story of values, aims, needs and challenges (Pearl 2013). Both approaches, however, necessitate the involvement of someone who knows the person very well, and are open to abuse. Questions arise such as:

- Does a certain facial expression or gesture really communicate agreement or could the opposite be the case?
- Does the person's life story of values really correspond to the decision being made?
- How well does the supporter really know the person with dementia and their values and needs?
- How long is it since the supporter spent much time with them?
- How close was this person, ever, to the person with dementia?

Skowron (2019) draws attention to the ambiguous nature of the term 'best interpretation', pointing out that it could be

referring to the outcome or the process of interpretation. A key issue is whether supporters should be doing their best, even when extremely difficult, to involve people in decisions about their lives or simply adopting the best approach to effective interpretation. Skowron suggests that "interpretation implies familiarity with the thing interpreted" (2019, p. 126) and that the Committee of the CRPD asks supporters to interpret the unknown rather than to determine it. One way of understanding the term 'best' in this context would be 'true' in the sense of one interpretation that is not better than another interpretation but rather one that is the closest to 'fact' (i.e. to what the person does actually want). A person's will and preferences are not, however, set in stone. Kvale and Brinkmann (2009) describe the collection of qualitative data using the analogy of a miner and a traveller, whereby data is not a treasure to be uncovered intact if you dig deep enough with the right tools but rather like a story that a traveller pieces together through interaction with people in the course of a journey and which is constructed and developed as a consequence of that interaction. The same could perhaps be said of a person's will and preferences. These do not lie there intact but are constantly constructed and reconstructed in a particular context within a changing environment and social context.

This has led to debates about different levels of will and a distinction being made between preferences related to a particular matter and more general beliefs and desires based on deeply held, reasonably stable and reasonably coherent personal values (Smuzkler 2017, cited in Skowron 2019). This is slightly reminiscent of Dworkin's (1993) experiential and critical interests and aside from the persistent problem of interpretation, there is a risk of deciding on other people's behalf what is most important to them, and failing to validate their right to evolve in terms of what they consider important in life. The experience of having a condition, such as dementia, can lead to significant changes in priorities and wishes and there is a risk of trapping people and failing to recognise their right to change.

Skowron (2019) concludes that 'best interpretation' is not solely an approach to be adopted as a last resort when it is impossible to determine people's will and preferences. Rather, it is a call to include people with disabilities in everyday interpretive practices, for clarity on how to interpret will and preferences in general, and for a realisation that will and preferences are not static but dynamic. This calls for attention to the way that people (including supporters) are always in some way making assumptions. It could also be understood within the context of the social construction of meanings.

### Combined supported decision-making model

In this last subsection, we consider a practical and ethical way forward based on the model developed by Scholten and

Gather (2018). They argue that supported decision making should not necessarily completely replace substitute decision making but should be perceived in the framework of reasonable accommodation. They propose a 'combined supported decision-making model' which combines supported decision making with competence assessment (2018). This is based on the view that it is sometimes permissible to deny people the right to make their own decisions but that this should only be the case for people whose functional decision-making capacity is substantially impaired and if all resources of supported decision-making have been exhausted.

The combined supported decision-making model respects and promotes the autonomy of people with dementia in three ways:

1. it respects the decisions of people with dementia who have decision-making capacity
2. it promotes the autonomy of people with dementia whose decision-making capacity is impaired by supporting their decisions and
3. it respects the precedent autonomy of people with dementia whose decision-making capacity remains impaired despite the provision of support by basing substitute decisions on the will and preferences of the person.

At the same time, it protects people with dementia who are vulnerable due to impaired decision-making capacity against abuse and undue influence.

The combined supported decision-making model proposed by Scholten and Gather (2018) consists of the following six steps.

1. **Presumption of decision-making capacity:** Everyone in our society should initially be deemed competent to make their own decisions and their decisions should be treated as carrying legal effect. This also holds for people with dementia.
2. **Rebuttal of the presumption:** The presumption of decision-making capacity can be rebutted only if there are concrete indications that a person might lack decision-making capacity. A diagnosis of dementia is not enough to rebut the presumption of decision-making capacity. A diagnosis of dementia is, however, a relevant factor, since dementia is a risk factor for impaired decision-making capacity (Kim 2010, pp.42-44). A diagnosis of dementia should trigger an assessment of decision-making capacity only if other factors also exist, for example, the person shows abrupt changes in their mental state, refuses recommended treatment or consents to particularly risky or invasive treatment (Grisso and Appelbaum 1998, pp.61-76). A refusal of recommended treatment should be considered in the context of the

stakes involved. This should be based on reflection about the balance between the consequences of refusal and the possible effects of treatment on the person's health, potentially resulting in a more structured assessment of a person's decision-making capacity.

3. **Assessment of decision-making capacity:** An assessment of decision-making capacity consists of a semi-structured conversation of 20-30 minutes about the decision to be taken. During this conversation, the assessor should assess whether the person is able to: (a) understand the potential consequences of the various options, (b) apply this understanding to their own situation, (c) evaluate the consequences of the treatment options in light of their values and commitments, and (d) communicate a treatment choice (Grisso and Appelbaum 1998, Kim 2010).
4. **Supported decision-making:** If the assessment shows that the person possesses the required abilities, they can make their own decisions and these decisions will carry legal effect. If, on the other hand, the assessment shows that the person's decision-making abilities are substantially impaired, supported decision-making should be provided in order to enhance the person's abilities and bring them in the position to make their own decisions. As examples of supported decision-making, Scholten and Gather (2018) mention everyday interventions (e.g. giving time to adapt or providing tranquil surroundings), interventions that improve the quality of the disclosure information (e.g. enhanced consent procedures), interventions that facilitate communication (e.g. plain language, braille or sign language) and social support from family, friends or peers. Support could also incorporate elements of shared decision making, subject to the person with dementia being in favour of such support.
5. **Monitoring:** During the provision of supported decision making, the conversation about the decision to be taken should continue and it should be monitored whether the support provided enhances the person's abilities up to a point at which they are in the position to make their own choices. In this process, it should also be monitored whether support people (consciously or unconsciously) exert undue influence on the person.
6. **Substitute decision making:** If it turns out that supported decision making enhances the person's abilities to a sufficient extent, they can make their own decision and this decision carries legal effect. If supported decision making proves insufficient and all reasonably available resources for support have been exhausted, a substitute decision maker should make a decision on behalf of the person. The guiding question for substitute decision makers is not what they prefer, nor what they would prefer if they were in the person's situation. Rather, they should ask themselves what the person would want in the situation if they had decision-making capacity. The answer to this question can be seen as the "best interpretation of the person's will and



preferences” (Szmukler 2019). Evidence for the person’s will and preferences is provided by (a) an advance directive, (b) previously communicated preferences with regard to the choice at hand, (c) the person’s values and commitments, and (d) the person’s best interest. This

is a prioritised list, meaning that substitute decision makers should make decisions based on, for example, the best interest of the person only if all the other sources of evidence about the person’s will and preferences are unavailable or insufficiently clear.

### Recommendations on legal capacity and decision making

1. The following recommendations should be considered in combination with those related to the various issues discussed in Part 4 of this report.
2. It should be presumed that a person with dementia has legal capacity unless:
  - there is reason to suspect that the person’s condition may be negatively affecting their decision-making capacity (not merely that they have a diagnosis of dementia) and
  - all possible measures have been taken to support them to make a particular decision and this has not been successful.
3. Any restriction of legal capacity:
  - should be in relation to a specific decision, skill or area of decision making
  - should take into account possible fluctuations of decision-making capacity and the possibility of someone being able to decide on the same issue on another occasion
  - should not be based on the assessment of a skill that a person has not yet acquired but may be capable of learning with time and support
  - should not be more extensive/far-reaching than necessary
  - should have been made after a legal or official procedure, recognised by the State and for which the person with dementia was involved, heard and supported
  - should be open to being challenged and
  - should not be irreversible.
4. The provision of necessary, relevant and timely support should be organised in a systematic and structured manner such as the combined supported decision-making model (please see pages 22-23).
5. People with dementia who lack legal capacity in relation to a particular decision or area of decision making (e.g. managing finances or making a will) should not be publicly labelled (e.g. as ‘incapacitated’ or ‘incompetent’) or asked to reveal such information unless strictly necessary.

## 4. Ethical issues related to the exercise of legal capacity in everyday life

In Part 4 of this report, we explore different issues and areas of daily life for which legal capacity and decision-making capacity are relevant to the lives and wellbeing of people with dementia. The topics addressed include:

- Guardianship,
- Treatment, care and support,
- Advance care planning,
- Participation in research,
- Coercive measures (including restrictions of freedom, the use of restraint and measures adopted during the COVID-19 pandemic),
- Civil and political life (including voting, marriage/partnerships and making a will/testament).

Each section includes a set of recommendations, which should be considered in addition to the general recommendations on legal capacity and decision making on page 23.

### Guardianship

Guardianship is particularly relevant to debates surrounding legal capacity and dementia. In this fourth section of the report, we will address broad issues linked to guardianship. As explained in the previous section, situations arise where some people with dementia are unable to make decisions affecting their own lives and wellbeing. Most countries still have legal provisions, which are applied in such situations and which result in some loss of legal capacity. The Committee on the Rights of Persons with Disabilities (2014) points out that substitute decision-making regimes can take many different forms, including plenary guardianship, judicial interdiction and partial guardianship. Article 27 of General Comment No. 1<sup>24</sup> provides details of certain characteristics that these regimes have in common, namely that they are systems where:

1. legal capacity is removed from a person, even if this is in respect of a single decision,
2. a substitute decision-maker can be appointed by someone other than the person concerned, and this can be done against that person's will, and

3. any decision made by a substitute decision-maker is based on what is believed to be in the objective 'best interests' of the person concerned, as opposed to being based on the person's own will and preferences.

Guardianship therefore refers to situations where a legal representative (a guardian) takes legally binding decisions for a person placed under a protective measure. Several countries use other terms such as curatorship, tutorship, legal representation, proxy decision making and surrogate decision making either instead of or alongside guardianship. In this report, we are using the term 'guardianship' as a generic term and in order to distinguish between the kind of substitute decision-making regime described above and other approaches to legal representation such as powers of attorney which can be granted and used irrespective of decision-making or legal capacity. Guardianship is also separate from supported decision making whereby a person is assisted in the decision-making process but retains the full power to make decisions under the law. The 'personligt ombud' (personal ombudsperson) is a system which operates in Sweden and is sometimes cited as a good example of supported decision making, reflecting the spirit of the provisions of article 12 of the CRPD depending on one's interpretation of it. It does not, however, replace guardianship measures which are still in force. Appendix 2 provides an overview of the support offered by a local NGO for ombudspersons in the county of Skåne.

Concerning the point made earlier about what constitutes autonomy, Shakespeare's concept of independence implies that having a guardian does not mean having no autonomy. On the contrary, the choice and control over possible assistance required should be considered as an example of the exercise of autonomy (Morris 2001). Nevertheless, insofar as the provisions of the CRPD are concerned, guardianship is not in keeping with respect for a person's legal capacity as it restricts or limits their right to make decisions that would be recognised by the law. The fifth paragraph of article 12 of the CRPD states that people with disabilities have the right to own property and to manage their financial affairs. The management of financial affairs is often a key aspect of guardianship measures for people with dementia.

<sup>24</sup> Corrigendum of 26 January 2018.

Whereas some guardianship measures consist of one measure which is sufficiently flexible to be adapted to the needs of the person designated as requiring support (e.g. in Germany), others have two or more different measures corresponding to the person's needs (e.g. in France and Luxembourg). Partial guardianship is often considered better in that it is linked to less loss of legal capacity as opposed to a global loss of legal capacity. Also, it is in keeping with the move away from totally depriving people of their legal capacity. This respects the principle of proportionality whereby the least restrictive measure should always be considered first. The difference between partial and plenary guardianship is not, however, always respected, resulting in guardians abusing their decision-making power and the people under guardianship not knowing which decisions the latter can and cannot take (Nilsson 2012). It should also be borne in mind that members of the public and even government officials do not always know the extent of a guardian's decision-making power. In situations where the person with dementia has difficulty making a decision and communicating it but has a known guardian who is present, there is a risk of the guardian being expected or asked to take certain decisions. This amounts to informal loss of legal capacity, based on ignorance and in some cases the desire for everyone concerned (except perhaps the person with dementia who might not even be aware that a decision is being made) to find a practical solution to a difficult situation. Procedures which can result in the global loss of legal capacity are diametrically opposed to the provisions of the CRPD and in many cases do not correspond to the real needs and capacities of people with dementia.

Within the context of guardianship, people have certain rights (e.g. to challenge decisions made on their behalf, to be present and heard during the legal process surrounding the measure and the accompanying loss of legal capacity, and to be notified). In practice, this does not necessarily happen. People wishing to challenge a particular decision do so as a person who has been legally declared as lacking legal capacity, and perhaps also as someone who has been malignantly positioned as 'defective' (Sabat 2008) and hence unable to decide what is 'good for them'. Awareness of this situation is likely to affect a person's self-esteem and confidence to challenge a decision. In some cases, there would also be relational issues involved and dilemmas linked to living with and being dependent on the guardian for care and support. This may also be applicable in the case of court procedures to determine legal capacity in that the person concerned may feel (probably rightly so) that they are already considered as lacking capacity by highly qualified healthcare professionals and often also by their families. It therefore takes a lot of courage, determination and self-confidence to go against the whole system alone (i.e. with no psychological and emotional support). In court procedures, the right to be present and heard can be denied on the grounds

that attendance in court would be detrimental to a person's wellbeing (Nilsson 2012). Nilsson argues that people should always retain the legal capacity to apply for the restoration of their full legal capacity within a certain period of time.

Mechanisms to monitor the activities of guardians often require annual reports, with the main focus on the management of financial assets. People under guardianship do not necessarily see these reports and in some countries, relatives who are guardians are not required to submit reports and their activities are not monitored (Nilsson 2012). This puts people with dementia who are under guardianship in a vulnerable position. The flaws in many guardianship procedures and practices result in people who are subject to them not being properly protected and in some cases open to abuse (e.g. guardians using their finances in ways they would not normally accept, putting them in care homes and dictating to them what they can and cannot do). Their lack of legal capacity puts them in a vulnerable position, which is the opposite of what is intended.

Procedures to assess decision-making capacity, where this still happens despite the requirements of the CRPD, and guardianship measures need to be transformed so as to provide reasonable accommodation to people with disabilities who are subjected to them. This also coincides with the requirement to provide access to support (mentioned in article 12.3). Such support should ideally not be provided by individuals with an interest in or link to the procedure or its possible outcome (e.g. such as relatives).

With regard to the points raised earlier about the problems of interpreting and implementing the provisions of article 12 of the CRPD, the recent Irish Assisted Decision-Making (Capacity) Act 2015 (Number 64) is an example of progress in promoting supported decision making but some would argue of failure to fully implement article 12. Section 14, for example, states:

*"(1) In exercising his or her functions as specified in the decision-making assistance agreement, the decision-making assistant shall –*

- a) assist the appointer to obtain the appointer's relevant information,*
- b) advise the appointer by explaining relevant information and considerations relating to a relevant decision,*
- c) ascertain the will and preferences of the appointer on a matter the subject or to be the subject of a relevant decision and assist the appointer to communicate them (.../...),*
- d) assist the appointer to make and express a relevant decision, and*

*e) endeavour to ensure that the appointer's relevant decisions are implemented*

*(2) A decision-making assistant shall not make a decision on behalf of the appointer*

*(3) A relevant decision taken by the appointer with the assistance of the decision-making assistant is deemed to be taken by the appointer for all purposes."*

There are also provisions covering the appointment of co-decision makers. The court nevertheless reserves the right to formally declare that a person lacks the capacity to make decisions relating to their personal welfare or property and

affairs (section 37) (even with the assistance of a co-decision-maker or where a suitable co-decision maker is not available) and to establish substitute decision-making arrangements on their behalf (section 38).

It could be argued that lawmakers are responding to the spirit of article 12 which is to start from the assumption that every person has legal capacity, including those with disabilities, but that they are leaving room to protect the rights and interests of people who cannot exercise their legal capacity, despite all possible attempts to support them, namely the particular situation on which the CRPD does not provide a coherent and meaningful solution.

### Recommendations on guardianship

1. Guardianship legislation should be reframed as decision-making support for which substitute decision making would be the most extensive level, only to be applied when all other options have been realistically considered or tested, and have not proven sufficient to protect the rights of people with dementia.
2. There should be no automatic loss of legal capacity or obligatory appointment of a guardian, even if a person with dementia lacks decision-making capacity in certain domains or situations, if a less far-reaching solution (e.g. a lasting power of attorney) can be found or a situation has not arisen for which a decision needs to be made.
3. Legislation and procedures related to such decision-making support should:
  - provide a structure which reflects the principles of shared and supported decision making, and reasonable accommodation
  - enable people to formally name any person currently providing support and/or sharing in the decision-making process (also in the context of substitute decision-making). This procedure should be flexible and unbureaucratic, designed to promote transparency, enable potential monitoring and help reduce the likelihood of abuse
  - enable people to formally request the future appointment of a particular person to act as guardian (i.e. legally appointed substitute decision maker), with the possibility to annul or amend this choice at any time. This includes the right to state such preference in an advance directive
  - not involve the automatic loss of any legal rights, such as the right to marry, divorce, vote, make a will, drive or make a contract. A guardian should not have the right to contract a marriage, divorce, make a will or vote on behalf of a person with dementia
  - promote the establishment of organisations providing trained and independent supporters and guardians (e.g. for people who prefer this solution or have no one else to take on this role)
  - ensure that the appointment of one or more substitute decision makers is established by means of a judicial procedure
  - ensure that this procedure is affordable and not unnecessarily burdensome
  - permit a sufficiently flexible approach to decision-making support that is proportionate to the actual needs and capacity of the person with dementia. This might involve a series of different measures or one measure which can be adapted to the person for whom it is intended
  - ensure that any actions taken by guardians correspond to the will and preferences of the person with dementia and are not primarily in their own interests or those of a third party
  - include measures to handle conflicts of interests between people providing decision-making support and the person with dementia
  - include measures for the anonymous reporting of suspected mistreatment or abuse of people with dementia by people actually or allegedly providing decision-making support.

4. With regard to the establishment of a guardianship measure (i.e. involving substitute decision making), people with dementia should:
  - be involved as much as possible in the process of setting it up and for the duration of the measure, including the choice of guardian and the guardian's duties
  - be seen and heard in person by the judge or equivalent authority
  - be allowed to appoint a person to speak on their behalf in court (without this altering the necessity to be seen and heard)
  - always be considered as having the legal capacity to challenge the appointment of a guardian, the loss of legal capacity or certain decisions made by a guardian (and be provided with necessary support to enable them to exercise this right if needed).
5. The activities of a substitute decision maker should be subject to supervision and regular review, and should be monitored by a judge or another independent authority. This should apply to all guardians, both appointed by the court and personally appointed, including relatives and close friends.
6. Everyone involved in decision-making support should be obliged:
  - to take into consideration the wishes of the person with dementia when trying to determine that person's will and preferences
  - to take into consideration the previously expressed wishes, values and preferences of the person with dementia (i.e. expressed in an advance directive or based on the knowledge of significant others)
  - to involve spouses, partners, relatives and close friends when making decisions on behalf of people with dementia unless it is impracticable or the person with dementia objects to their involvement
  - to inform and consult the person with dementia about decisions being made even when they lack decision-making capacity. Information should be given in the way most appropriate to the person's remaining capacity
  - to ensure that the finances of people with dementia are used for their direct and current benefit (if and when appropriate and desired by the person concerned) and not to have as principal aim the augmentation or maintenance of their capital (unless this corresponds to the clear wishes of the person concerned)
  - to keep track of support provided (formal records in the case of substitute decision making) for the sake of transparency and accountability (if challenged).

## Treatment, care and support

We have already explored some of the key issues and debates related to supported decision making. In this section, we focus on issues related to medical treatment, care and support, particularly with regard to informed consent and to situations where this cannot be provided by people with dementia.

### Informed consent

There are a few important documents of relevance to the ethical conduct of medicine, such as the Nuremberg Code, which was introduced in 1947 after the trial of doctors in the wake of World War II, the Declaration of Geneva of 1948 and the physician's oath known as the Hippocratic Oath, which set out guidelines for members of the medical profession based on humanitarian and ethical standards for treatment and care. In the context of medical treatment and care, doctors have a duty, under the Hippocratic oath, to act in each patient's best interests and to refrain from exploiting their patients. This fiduciary relationship between doctors and their patients is the cornerstone of ethical clinical practice. The relationship of trust is based not only on personal and

professional integrity but also on patients' expectation that doctors (and other healthcare professionals where appropriate) have the necessary expertise and training to justify putting their health and wellbeing into their hands. According to Beauchamp and Childress (2001, p.430).

▶ *"The patient-physician relationship is a fiduciary relationship—that is, founded on trust or confidence; and the physician is therefore necessarily a trustee for the patient's medical welfare."*

Patients must nevertheless be asked to provide informed consent to any treatment they are offered by a doctor (and are of course entitled to withhold consent and refuse the treatment - subject to certain exceptions). Decision-making capacity remains in many situations the condition for valid informed consent, based on widely accepted criteria, including:

- the ability to understand information relevant to the decision, including that related to risk,
- the ability to retain, use and weigh up such information, to relate it to one's own values and goals, and the likely consequences of deciding one way or the other,
- the ability to communicate a choice.

There are, however, numerous decisions that doctors and other health and social care professionals do not make with patients because they are part of the process of a professional evaluation of different options, drawing on their knowledge and expertise (e.g. which boxes to tick on a request for a blood analysis or which type of scan to propose), which occurs before it is decided what to offer the patient (whether or not to have a blood test or scan to help identify the cause of their problem). This still reflects the fiduciary relationship and respects the autonomy and dignity of patients.

In the vast majority of cases, such trust is well-founded but the fiduciary relationship rests on the principle of best interests, which is increasingly being challenged on the grounds that it is paternalistic (unless used solely as a last resort). People are questioning whether the doctor really does know what would be best for them but also how to balance trust and reliance on the fiduciary relationship with respect for autonomy. As mentioned earlier, there are ethical arguments which emphasise the importance of respect for autonomy, dignity, individuality and freedom. They are based on the premise that people are best placed to know what is best for them and that they should confirm what it is that they want, based on the information and options provided. Some people may do this on the basis of blind trust in the members of the medical profession, their own gut feeling or evaluation of options and/or consultation with others and nowadays, of the Internet. When a person is deemed as having legal capacity, 'gut feeling', blind trust and various approaches not reflected in the above criteria would usually go unquestioned. For people who lack or are assumed to lack decision-making capacity or whose legal capacity has been restricted, this is not necessarily the case.

A rigid application of article 12 of the CRPD would help prevent such discrimination where decisions are made by other people with potentially different values, principles, life experience and world views to the person in whose interests they claim to be acting, on the basis of best interests. Many people (because they have dementia or for other reasons) have difficulty organising their thoughts and feelings about a particular issue, understanding what is at stake and the implications of different options for them and communicating what they want. This is not a reason to exclude them from the process but rather a reason to provide them with the support they need to make a particular decision, and this is the spirit of the provisions already described in the CRPD.

Informal restrictions of legal capacity in relation to treatment, care and support occur when people with dementia are not consulted about decisions, not only those which

may have an obvious and significant effect on their lives and wellbeing but also on the many small decisions that people all take every day. They might, for example, not be told that they are entitled to some form of support because it is expensive and they live with someone who has not objected to providing a particular aspect of care. A health-care professional might agree with an informal carer not to propose some kind of therapy that might require them to accompany the person to an appointment every week. Similarly, someone might not be told that there is an alternative form of treatment available, which might have fewer side effects, compared to the treatment they have been on for over a decade etc. Consequently, the decision to continue taking the medication and suffering the side effects does not constitute ongoing informed consent.

Some decisions, for which people's legal right to be involved in decision-making is overridden, are literally a matter of life and death. There have been reports during the COVID-19 pandemic of the blanket use of DNAR ('do not attempt resuscitation') orders for people in care homes, often without the knowledge of the residents, their families or their guardians. This was the case for many people with dementia but also people with other conditions such as autism and Down's Syndrome. It resulted in ambulances and doctors not being called when urgently needed. There are risks involved in DNARs (i.e. attempting cardiopulmonary resuscitation) such as punctured lungs, broken ribs and severe bruising, which people need to be aware of. However, the blanket application of DNARs and the failure to appraise the individuals concerned and involve them and/or their loved ones (if they lack decision-making capacity) has been described as totally unacceptable and a breach of people's human rights (BBC 2020b).<sup>25</sup>

Covert medication involves the intentional administration of medication in a disguised form, usually in food and drink, resulting in someone unknowingly taking medication (i.e. without their consent).<sup>26</sup> The Mental Welfare Commission for Scotland (MWCS) (2017) has issued good practice guidance on this which emphasises the need to establish necessity, the legality of such an act, and whether it is proportionate in relation to benefit and potential distress. The Commission suggests, for example, the need to consider whether covert medication might sometimes be the best way to avoid administering medication by force, which would be degrading. It also emphasises the need to provide support, consult relevant people (relatives, close friends, welfare attorneys or guardians), as well as advance statements, and to take into consideration past and present known wishes. As with capacity to consent to treatment in general, covert medication to a person

<sup>25</sup> The UK Care Quality Commission (CQC) is undertaking further fieldwork across seven clinical commissioning groups to understand the extent to which DNARs may have been misused during the pandemic. A final report is due to be published in February 2021.

<sup>26</sup> When the covert medication is aimed at controlling or changing someone's behaviour, it would be classed as chemical restraint (see page 44).

who has capacity to consent would be considered assault and a breach of human rights. The MWCS guidance contains examples of covert medication care pathways which provide a means to record how decisions are made and potentially to defend or challenge specific covert medication decisions. It should, however, be noted that medicines are usually licensed to be administered in a certain way and that tablets, capsules and liquids may become 'unlicensed' when crushed, emptied or mixed with other liquids.

The issue of implicit consent to various forms of medical treatment is often overlooked. Medication is frequently prescribed or handed out in hospitals and care homes (without even the packaging or patient information leaflet to indicate what it is). Many patients obediently take the prescribed medication, thereby implicitly consenting to it. Requests for clarification are received in various ways, ranging from irritation about taking up precious time to oversimplified/

euphemistic explanations, with a proper explanation lying somewhere between the two. This may leave people not knowing what the medication is for, whether there are potential side effects and what the consequences would be of not taking it. The compliance of a person known to be lacking decision-making capacity (i.e. to take or not take one or more tablets) cannot be considered as implicit consent in the same way that it might for a person who has decision-making capacity but decides not to bother and just to take the tablet on the basis of trust (coming back to the fiduciary relationship with healthcare professionals). It cannot be assumed that the medication is necessary. It might, for example, be a sedative, administered at the discretion of nursing staff for their own tranquillity. The issue of unequal power relations between people with dementia, who are dependent on others for care or treatment, and those responsible for various treatment and care, must also be considered.

### Recommendations on treatment, care and support

1. All treatment, care and support of a person with dementia should require that person's informed consent (see also conditions and exceptions mentioned in the recommendations on legal capacity and decision making, and on guardianship).
2. Consent should be voluntary, informed and made by a person who has the capacity to decide on the particular issue, with as much appropriate support as needed.
3. The consent to or refusal of a particular treatment should be respected even if detrimental to the person's health and wellbeing if such consent or refusal reflects that person's wishes (if they have legal capacity) or has been made in an ethical manner (taking into account the person's will and preferences) by a person or people legally authorised to consent on their behalf (if they lack legal capacity).
4. 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 prior consent.
5. Whenever medication is administered through food and drink to a person who has the capacity to consent, that person must be informed and provided with the reason for this approach as well as details of the medication administered in that way.
6. Covert medication should only ever be a last resort, based on a team decision and part of a clear covert treatment plan.
7. Covert medication should be regularly reviewed (at least once a week), should not be extended to additional drugs without further review and should be recorded.
8. Relatives and loved ones should be consulted, where appropriate, in order to reflect on ways to encourage a person with dementia (who lacks the capacity to consent) to take necessary medication.
9. Advice should be obtained from a pharmacist about whether, and if so how, a particular form of medication can be safely administered in another way (e.g. opening capsules or crushing tablets).
10. People with dementia should be permitted to communicate their consent (or refusal of consent):
  - verbally (e.g. the person saying that they agree to a particular treatment)
  - in writing (e.g. the person signing a consent form, after having read and understood it)
  - non-verbally (e.g. by holding out an arm for a blood test).
11. In emergency and life-threatening situations, where there is no time to obtain informed consent from the person with dementia or from other people authorised to provide substitute consent, treatment or care should be provided and the reasons for this explained to the person and any substitute decision makers afterwards.
12. Do not attempt resuscitation orders (DNARs) should always be made on an individual basis, with the involvement of the person concerned and, where appropriate, with that of relatives and informal carers.

13. DNARs should never be applied as a blanket measure, must not be discriminatory and should not be based on assumptions about quality of life.
14. People with dementia who are living in a precarious situation or in extreme unsanitary conditions, which endanger their lives or put others in danger, should be taken to a place of care in accordance with established legal procedures. See subsection on involuntary placement (p.39).
15. All consent should be recorded and monitored.
16. People with dementia should be informed of their right to question decisions made by service providers and substitute decision makers about their treatment, care and support.
17. People with dementia should be offered support (e.g. by a neutral person such as an ombudsperson) if they wish to file a formal complaint.

### Communicating the diagnosis of dementia

Irrespective of whether legal capacity is dependent on decision-making capacity, if people have the right to make autonomous decisions, they should also have the right to receive information relevant to the issue to be decided. The communication of a diagnosis of dementia is central to the promotion of autonomy because people need that information when weighing up the pros and cons of issues such as continuing to live alone, whether to continue managing personal finances or seek decision-making support and so on. It is a matter of trustworthiness, which might be described as a virtue to strive for (e.g. in virtue ethics). It is also linked to respect for a person's dignity, which is essential when providing support for decision making. Article 10 (Private life and right to information) - paragraphs 1 and 2 - of the Council of Europe's Convention on Human Rights and Biomedicine states:

- ▶ 1) *“Everyone has the right to respect for private life in relation to information about his or her health.”*
- ▶ 2) *“Everyone is entitled to know any information collected about his or her health. However, the wishes of individuals not to be so informed shall be observed (Council of Europe 1997).”*

Knowledge of the diagnosis may, amongst other things, give the person with dementia the possibility to:

- confirm suspicions and put an end to uncertainty,
- gain a better understanding of difficulties they are experiencing,
- come to terms with personal changes and losses caused by the disease,
- obtain information about the progression of the disease, treatment, care and services,
- develop positive coping strategies and set short-term goals,
- give informed consent for anti-dementia drugs and/or to participate in clinical trials,
- make decisions about future care preferences,
- write an advance directive,

- sort out personal finances and take decisions regarding property and assets.

Another ethical consideration, sometimes mentioned by those not in favour of informing people with dementia of their diagnosis, is non-maleficence (i.e. not causing harm), accompanied by the belief that it would be beneficent to withhold such information. A third article of the above Convention provides for the right to be informed to be overridden in certain circumstances. Harm is sometimes described in terms of harm to the doctor-patient relationship and ‘unnecessary’ psychological harm (van den Dungen et al. 2014). This may reflect views that nothing can be done (Moore and Cahill 2012) and fails to recognise the potential harm that not knowing or vague or ambiguous information may have on people with dementia (Bamford et al. 2004).

In keeping with respect for legal capacity, the desire not to be informed must be respected because it represents the exercise of autonomy. There is, however, a grey zone when it comes to interpreting the will and preferences of people who have difficulty communicating and of opting in favour of non-disclosure on the grounds that the person would not understand or would be distressed. These may be genuine concerns, as opposed to paternalistic attitudes or the wish to avoid a difficult situation. Keightley and Mitchell (2004) describe some of the pros and cons of disclosure as follows:

- ▶ *“Although by being truthful you may confirm someone's worst fears, you also give them the opportunity to come to terms with the situation and work through their feelings. Without a diagnostic framework within which to understand their experience many people with dementia will be left frightened that they are going mad with little or no support.”*

Nevertheless, the emphasis should be on supporting people with dementia to decide whether or not to be informed of the diagnosis and not on someone else making that decision. Just as people with dementia are entitled to take risks, they are also entitled to experience emotions, which are natural, human responses to events in life and may be beneficial in



coming to terms with what they are experiencing as a result of having dementia. Medical professionals may need support to communicate diagnoses to people with dementia.

Three recent systematic literature reviews of the diagnosis of dementia all report that the majority of people with and without cognitive impairment, within the primary care context as well as in memory clinics, prefer to be informed of a possible diagnosis of dementia (Werner, Karnieli-Miller and Eidelman 2013, van den Dungen et al. 2014, Low, McGrath, Swaffer and Brodaty 2018). On the other hand, it should be borne in mind that some people do not want to know and state this very clearly (Marzanski 2000). In some countries, there is increasingly a greater focus in policy and practice on promoting timely diagnosis and on asking people during the diagnostic procedure if they want to know their diagnosis and if not, whom they would like to be told on their behalf. Van den Dungen et al. (2014) also suggest cautiously exploring reasons not to be informed to help identify fear or misunderstandings about dementia.

Some carers do not want the person with dementia to be informed (Shimizu et al. 2008, Quinn, Jones and Clare 2017, Zou et al. 2017). The practice of disclosing the diagnosis to carers and not to people with dementia used to be quite common (van Hout et al. 2006). In a more recent study about timely diagnosis in the Czech Republic, Finland, Italy, the Netherlands and Scotland, considerable differences regarding disclosure of the diagnosis (based on caregiver reports) were revealed:

► *“In all countries except Italy, the diagnosis was usually disclosed to the person with dementia by a health care professional. In Italy, 60% of the carers reported that the person with dementia had not been told the diagnosis, compared with 1.1% in Finland and 4.4% in Scotland, 8.2% in the Netherlands, and 23.2% in the Czech Republic. (.../...) The reasons for nondisclosure fell into 4 main categories: not wishing to upset the person, the person would not understand or was not aware, the family thought it unnecessary, and the doctor advised against telling the person. Across all countries, the diagnosis was less likely to be disclosed to a person with dementia that was late stage or severe (54%) compared with middle (69%) or early stage (80%), and this contributes to the higher nondisclosure rates in Italy and the Czech Republic, but notably over half of those diagnosed in the early stages of dementia in Italy were not informed” (Woods et al. 2018).*

Informing relatives of a diagnosis of dementia, without the knowledge or agreement of the person with dementia,

does not respect the right of people with dementia to privacy and breaches medical professionals' obligations with regard to confidentiality. It is unethical as it fails to respect people's autonomy and it may run counter to the principles of beneficence and non-maleficence (although such concepts are sometimes used to defend non-disclosure). Furthermore, it places a potential burden on carers to disclose the diagnosis to the person with dementia themselves even though they are unlikely to be equipped with the necessary information and understanding of the condition to be able to carry out this task effectively, and might not even be in favour of sharing the diagnosis.

It should not be assumed that because someone has a diagnosis, they necessarily accept it or want to talk about having Alzheimer's disease, for example. Some people may be aware of their diagnosis but prefer to refer to the condition by a different name (e.g. preferring to talk about having 'memory problems') (Clare, Quinn, Jones and Woods 2016, Quinn, Morris and Clare 2018).

Bailey, Dooley and McCabe (2018) emphasise the need for doctors to tailor communication of the diagnosis to their patients' preferences and awareness. They also need to consider which information can be discussed in the presence of carers and to create the right balance between honesty and hope when discussing prognosis and medication, bearing in mind how cognitive impairment affects understanding. Bailey et al. point out that misunderstandings may limit the opportunities that people with dementia have to take an active role in decision making, and hence in exercising their legal capacity, otherwise offered by timely diagnosis. Disclosure is a delicate, complex and nuanced task. It can also be emotionally challenging, and many healthcare professionals would benefit from training and supervision.

The need to respect and promote people's autonomy, by allowing them to choose whether or not to be informed of a diagnosis (rather than other people deciding on their behalf) and to manage any disclosure in a sensitive and appropriate manner, is reflected in the National Dementia Strategy (Department of Health 2009) of England:

► *“Objective 2: Good-quality early diagnosis and intervention for all. All people with dementia to have access to a pathway of care that delivers: a rapid and competent specialist assessment; an accurate diagnosis sensitively communicated to the person with dementia and their carers”.*

### Recommendations on communicating the diagnosis of dementia

In order to be in a position to exercise legal capacity, the following recommendations surrounding the disclosure of the diagnosis are proposed.

1. People with dementia should have a legal right to decide whether or not to be informed of their diagnosis.
2. Whilst care should be taken to avoid causing unnecessary anxiety and suffering, information about the diagnosis should not be withheld solely on the grounds that a person has dementia, memory problems and/or communication difficulties.
3. People with dementia have the right to choose/authorise who (if anyone) should be informed of the diagnosis on their behalf or in addition to themselves and to specify anyone who should not be informed. Responsibility for the disclosure of the diagnosis should be clear and transparent.
4. It should be documented whether, by whom and to whom the diagnosis has been communicated.
5. The diagnosis, if disclosed in accordance with the wishes of the person with dementia, should be communicated clearly.
6. Medical professionals should directly ask their patients, sensitively and in advance, whether they would like to be informed if they had dementia and about their preferences regarding other people (e.g. their relatives) being informed.
7. The next of kin, partner and potential carers of the person with dementia should be informed of the diagnosis of dementia if they so request, provided that the person with dementia agrees to this and does not, or did not previously, request that they should not be informed. Healthcare professionals should encourage people with dementia to involve relatives and close friends in the disclosure procedure.
8. Medical professionals should not reveal the diagnosis to close relatives, friends and/or carers of the person with dementia as a means to avoid personal responsibility for communication of the diagnosis to the person with dementia.
9. Medical professionals who do not inform their patients of a diagnosis of dementia should be obliged to record this in the patient's medical file, along with a justification for this decision.
10. People who are informed of someone else's diagnosis of dementia in connection with their work (either voluntary or paid) should be obliged to treat such information with confidentiality.
11. Additional information should be provided in a timely manner (i.e. when the diagnosis is disclosed or soon after, see below). This should include information about the person's general state of health, prognosis, treatment possibilities, and potential risks and side-effects of anti-dementia drugs. It should also cover psychosocial and non-pharmacological approaches to managing symptoms and cognitive decline, the availability of services to which the person is entitled, the name of the doctor who will have overall responsibility for the person's ongoing care/treatment, and a discussion about advance care planning.
12. Written information should always be provided as a back-up.
13. People with dementia may have difficulty taking in all the information provided at the time of diagnosis and be in a state of shock. For this reason, it should be possible for them to have a second meeting with their doctor at a later date in order to obtain further information/clarification concerning the diagnosis. They should also have access to other forms of post-diagnostic support.
14. Every person diagnosed with dementia should be provided with up-to-date contact details of the national and local Alzheimer associations at the time of diagnosis, along with information about the kinds of services and support that the associations offer and information about local services.
15. A system should be devised in order to ensure that all relevant medical professionals receive appropriate and up-to-date information about Alzheimer associations and local support services. It may be necessary to work in close collaboration with the State and/or professional medical bodies/associations in order to achieve this goal.
16. Attempts should be made to provide comprehensive information in such a way as to maximise the ability of the person with dementia to understand. Attention should be paid to any possible difficulty understanding, retaining information and communicating, as well as the person's level of education, reasoning capacity, current understanding of dementia and cultural background.
17. More guidance should be developed and training made available to healthcare professionals on how to communicate a diagnosis of dementia.
18. The above-mentioned rights relating to the disclosure (or non-disclosure) of a diagnosis of dementia should be covered by national legislation.

## Advanced care planning and advance directives

Advance directives help ensure that a person's decisions about care and treatment are respected even when they are no longer able to make and express them. They should ideally be made in the context of comprehensive advance care planning. There is a considerable body of research and philosophical debate on the issue of personhood and person status in relation to advance decision making (e.g. whether the person making the advance directive is the same person as the one for whom it will eventually be used, if not why an advance directive should be respected and whether some people should still be considered as 'persons' at all etc.).<sup>27</sup> As Mäki-Petäjä-Leinonen (2016, p.148) points out, "the way we approach changes in capacity is thus revealing of our understanding of personhood as it forces us to pose the questions of whether the person remains the same or becomes different". Our focus here is on the issue of legal capacity, noting that advance directives come into force when and only when it has been established that decision-making capacity has fallen below a certain threshold deemed necessary to make a particular decision (Parker 2016, p.391). Nevertheless, the philosophical questions remain and cannot be easily separated.

Scholten and Gather (2018) and Scholten et al. (2019) note that respecting wishes expressed in an advance directive is dependent on recognition that a person, at the time that a decision needs to be made, lacks the ability to make it. This justifies non-respect of their current legal capacity (i.e. serving as an instruction for health and social care professionals not to act in accordance with current wishes but in accordance with those expressed in the advance directive). A diagnosis of dementia is not sufficient to justify overriding current wishes. If a person is able to make a particular decision, it should be respected. This brings us back to the issue of what it means to make a decision and how decision-making capacity is linked to legal capacity. Some writers emphasise the need to balance previously expressed wishes and current wishes, by exercising "careful thought, compassion and wise judgement" in each case taking into account the impact on the person with dementia if their current wishes are not granted (Hope and McMillan 2011, Mäki-Petäjä-Leinonen 2016). Proponents of a critical interests approach would emphasise, rather, the importance of historical lifetime values and beliefs.<sup>28</sup>

The concept of advance directives seems to run counter to the provisions of article 12 of the CRPD with regard to every person being considered as having decision-making

capacity and no one being deprived of their legal capacity (Scholten et al. 2019). Nevertheless, as Scholten and Gather (2018) point out, the Committee promotes the right of people with disabilities to engage in advance planning, describing it as an important way to inform others of their will and preferences at a time when they may be unable to do so. The use of advance directives could therefore be seen as useful merely when people are unable to communicate their will and preferences or also within the context of supported decision making, even for 100% support. However, the latter would not logically be possible because supported decision making is based on a person retaining legal capacity whereas an advance directive comes into force when a person has been declared as lacking legal capacity. Advance directives are legal documents in many countries, for which refusals of treatment are considered as legally binding, and their entry into force is dependent on assessments of decision-making capacity resulting in the loss of legal capacity.

People should have the right to decide how future decisions related to care and treatment are handled. This might involve making no plans, appointing someone to decide on their behalf, making an advance directive or combining an advance directive with a designated person with authority to override wishes expressed therein. The CRPD calls for an end to substitute decision making but advance directives can be used precisely to appoint a substitute decision maker or to prevent substitute decision making. Surely, people should be free to choose to draw up a document that comes into force upon loss of their decision-making capacity, resulting in loss of legal capacity. Scholten and Gather state,

► *"Indeed, it is precisely the point of advance directives that a person's treatment preferences when competent should override her preferences when incompetent"* (2018, p.230).

Moreover, an advance directive can be withdrawn at any time and in most countries the right to withdraw a directive is not dependent on the same level of decision-making capacity as that required to make one. This raises questions about what is considered an acceptable level of support, how assessments of capacity are made and about the conditions for withdrawing an advance directive, especially when a person is already considered as lacking the legal capacity to draw one up.

Advance directives are often too broad or too narrow and do not fit neatly to the situation and decision to be made.

<sup>27</sup> See also Alzheimer Europe's report on the use of advance directives by people with dementia (2006) and on ethical challenges affecting the involvement of people with dementia in research (2019) for more details about our position and a summary of some of the key debates: <https://www.alzheimer-europe.org/Publications/Alzheimer-Europe-Reports>

<sup>28</sup> See Dworkin R (1993). *Life's Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom*. Vintage Books.

Scientific advances are constantly being made which have possible implications that the person did not know about when the advance directive was drawn up. Alzheimer Europe advises people to consider this and whether they might want to designate in the advance directive a person to help with the interpretation of their wishes, and even to override them if they do not seem to reflect the spirit of the person's known will and preferences.

The use of advance directives is often considered in the context of isolated decisions but decisions often concern issues that build on others and span across periods of time. They also have implications for other people, which emphasises the need to involve significant others when drawing them up and/or to inform them of choices that have been made. Advance directives can be incorporated into a more relational,

ongoing approach to decision making and autonomy but the issue of their validity resting on decision-making capacity and loss of legal status remains problematic and an ethical dilemma, namely that the means to exercise autonomy is dependent on loss of legal capacity which according to the CRPD fails to recognise the right to exercise autonomy.

Finally, legislation, which requires advance directives to be renewed at regular intervals (e.g. every 5 years) and considers those which are not renewed as invalid, discriminates against people who lack the decision-making capacity required to renew an existing advance directive and yet may live a further 20 years or more. Their wishes might not have changed but their advance directives are no longer considered as legally binding because of their loss of legal capacity to renew them.

### Recommendations on advance care planning and advance directives

1. Governments should:
  - provide a clear statutory basis for effective advance directives with appropriate safeguards and a framework of procedures to ensure their effectiveness
  - set up appropriate systems for the registration, use and review of advance directives
  - legally recognise the role of proxies, appointed by the authors of the advance directives, and develop relevant safeguards for their involvement in the interpretation of wishes described in the advance directive or in decision making
  - raise awareness amongst the general public and health and social care professionals about the use of advance directives, including potential advantages as well as possible risks.
2. Doctors should not follow instructions/wishes expressed in the advance directive if the person currently has the capacity to make a particular decision in a particular situation, with or without appropriate support.
3. Due consideration should be taken of the person's currently expressed wishes, needs and fears even for decisions which the person is unable to make even with support.
4. Decisions not to comply with wishes expressed in valid advance directives should be documented in patients' medical files and an explanation should be given to significant others, relevant supervisory bodies and healthcare proxies.
5. People should be allowed to confirm their desire for their advance directive to remain valid should they at some point lack the capacity to renew it or to transfer decision-making responsibility to a named person of their choice.
6. Legislators should consider a clause allowing people, if they so wish, to determine their own conditions for the entry into force of their advance directives and of the possible role of a trusted person/healthcare proxy (substitute decision maker) in this process.
7. Due to difficulties in obtaining an appropriate level of precision (which is neither too vague nor too specific to be of practical use), people should be encouraged:
  - to consult doctors and other qualified healthcare professionals when considering whether/how to draw up an advance directive within the context of advance care planning
  - to write statements of values in addition to advance directives
  - to discuss wishes about future care and support with relatives and any appointed healthcare proxies.
8. In order to guarantee equity in the provision of health care and to ensure that people have a real choice, the availability of and access to good quality palliative and end-of-life care services/facilities for people with dementia should be improved.

## Participation in research

Research is a general term which covers all kinds of studies designed to find responses to worthwhile questions by means of a systematic and scientific approach. It covers a vast range of studies, involving a multitude of approaches and numerous disciplines (e.g. psychology, sociology, biology, genetics, ethics, law and anthropology). There are many different ways to carry out research but roughly speaking there are two main approaches, namely qualitative and quantitative. Increasingly, both approaches are used in the same study even though each is historically rooted in a different philosophical paradigm.

In 1964, building on the Nuremberg code and the Declaration of Geneva (mentioned earlier), the World Medical Association adopted a set of ethical rules and regulations to be applied to research involving human experiments. (e.g. to biomedical, experimental and clinical research). Whilst not legally binding or enforced under international law, it was developed by the medical community and has become a cornerstone document for human research ethics. There are numerous frameworks and documents to guide researchers in the conduct of ethical research such as the biomedical ethical principles of Beauchamp and Childress (2001) which emphasise not only respect for persons (their autonomy and dignity), beneficence (doing what is good for someone) and non-maleficence (i.e. protection from harm), but also the need for justice/equity. Another example is the ethical criteria for clinical research described by Emanuel et al. (2000) which provides guidance to help ensure that clinical research is robust, has value and is meaningful, providing society with accurate answers to questions that were worth asking. It covers: 1. value (linked to the enhancement of health or knowledge), 2. scientific validity (methodologically rigorous), 3. fair subject selection (guided by scientific objectives not vulnerability or privilege, with a fair distribution of risks and benefits), 4. a favourable risk-benefit ratio, 5. independent review (with the possibility to approve, amend or terminate studies), 6. informed consent and 7. respect for enrolled research participants (protection of privacy, possibility to withdraw and monitoring of participants' wellbeing). These principles and guidance were developed in the context of biomedical and clinical research but have been adopted and used in a much broader research context.

Some research (e.g. clinical trials and some biomedical and/or genetic research) is governed by specific laws, which do not apply to other forms of research. However, all research must be conducted within the constraints of a legal and ethical framework, reflecting amongst other things the need for informed consent (or appropriate substitute consent), respect for human dignity and compliance with safety and data protection requirements.

## Informed consent and equity

The principle of informed consent is also one of the most fundamental foundations for the conduct of ethical research and, in addition, a legal prerequisite for the conduct of biomedical and some forms of clinical research. The aim of informed consent is to protect participants from harm (in keeping with the principle of non-maleficence) whilst respecting their autonomy and avoiding deception or coercion (Beauchamp and Childress 2001). It is also linked to the principle of justice in that people who seem unable to consent, but were not provided with accessible information and appropriate support, may be wrongly deprived of treatment or of the opportunity to take part in research, or on the contrary given treatment or involved in research which might not correspond to their will and preferences.

Involving people in research without their consent could be considered illegal if legislation (e.g. in relation to clinical trials) stipulates that a person must give informed consent and that to do so, they must have decision-making capacity. The MacArthur Competency Assessment Tool for Clinical Research (MacCAT-CR) (Appelbaum 2007, Appelbaum and Grisso 2001) is sometimes described as the 'gold standard' for the assessment of capacity to consent to clinical research, although not necessarily on its own (Howe 2012).

Strict formal requirements for the participation of people from vulnerable groups in research exist based on national laws but also on European and international treaties such as the Convention on Human Rights and Biomedicine (1997) and the Declaration of Helsinki (1964) and the Nuremberg Code (1946). In such cases, lacking the capacity to give informed consent not only results in participation being dependent on the decision of a substitute decision maker but also on different conditions for participation being applied (e.g. linked to risk and burden) and having little or no say in the matter. Nevertheless, it could also be argued that such provisions make it possible to involve people in research who, historically, were totally excluded.

The Council of Europe's Additional Protocol on Human Rights and Biomedicine (2005) only allows people who are unable to consent to participate in biomedical research without a direct benefit if the research entails only minimal risk and minimal burden. Additionally, article 15 of this document further stipulates that the results must have the potential to produce real and direct benefit to participants' health, that the research could not be carried out on people capable of giving consent, that the potential participants have been properly informed of their rights and of safeguards, that authorisations from legal representatives have been obtained, that previously expressed wishes have been taken into account and that the potential participants have not objected to participation. The issue of direct benefit may be side-stepped subject to fulfilment of

the above-mentioned conditions provided that, amongst other conditions:

- ▶ *“the research has the aim of contributing, through significant improvement in the scientific understanding of the individual’s condition, disease or disorder, to the ultimate attainment of results capable of conferring benefit to the person concerned or to other persons in the same age category or afflicted with the same disease or disorder or having the same condition; the research entails only minimal risk and minimal burden for the individual concerned; and any consideration of additional potential benefits of the research shall not be used to justify an increased level of risk or burden.”*

In this example, loss of legal capacity means more than loss of the right to make decisions; it means that the people so deprived of their legal capacity cannot participate according to the same rules and conditions applied to other people. There is no longer a level playing field. People with dementia who are unable to give informed consent (according to fairly rigid standards which do not necessarily reflect shared or supported decision making) would not, for example, have the right to take part in research into a new drug treatment to prevent heart disease or to be a control in a clinical trial (valid reasons for exclusion aside). People with dementia may still find themselves unfairly excluded from research because of biased sampling approaches, discriminatory inclusion and exclusion criteria, gatekeepers who are either being over-protective or thinking about their own wellbeing or decisions made by ethics boards (Alzheimer Europe 2019). Denying people with dementia the same opportunities that other people have with regard to participation in research amounts to an informal restriction of legal capacity.

### Risk assessment

Assessments of risk, benefit and burden cannot easily be made for whole groups of people and there is a risk of paternalism, leading to a lot of people being overprotected and excluded from research without having any say in the matter. Drawing on a relational ethics perspective, Fisher (2009) suggests that:

- ▶ *“Formulating regulations and ethical judgments solely on the bases of opinions expressed by experts in the scholarly community and IRB members risks treating subjects as ‘research material’ rather than as moral agents with the right to judge the ethicality of investigative procedures in which they participate” (2009, p.5).*

As unique individuals, people with dementia have their own perceptions of danger and of the level of risk that they are willing to take. This is also the case with regard to evaluations of potential benefit. There is therefore a risk of overprotecting people with dementia, infantilising

them and depriving them of their autonomy (Jongsma and Schweda 2018).

Casarett and Karlawish (2000) highlight the changing nature of priorities in relation to risk, pointing out that when approaching death, for example, the things that some people find important may change, with a greater value being placed on dignity, meaning, control and strengthening relationships amongst other things. Similarly, a person who is very close to death might not assess the possibility of serious risk in the same way as a person who has not yet reached that stage. Some risks may be considered as being more significant and others less so (Casarett and Karlawish 2000). This depends greatly on the individuals concerned and on their awareness and understanding of their prognosis. People who are considered as lacking capacity, partly based on their perceived inability to assess risks and the personal relevance to them, may sometimes be denied the right and opportunity to do something that is in keeping with their values and goals in life by others who may have difficulty coming to terms with their own inevitable loss and in acting in accordance with the known will and preferences of the person with dementia.

Participating in research may, for some people at various stages of dementia, correspond to new priorities. Legislation and practices which deprive them of their formal or informal legal capacity interfere with their dignity and right to autonomy. Some would consider current legislation and guidelines, which restrict legal capacity, as over-restrictive and as being overly focused on non-maleficence at best, and as representing hard paternalism at worst. On the other hand, allowing everyone the right to decide whether or not to participate in research irrespective of their understanding of the risks and benefits (if any) involved could be perceived as failure to protect vulnerable people from exploitation and abuse.

### Proxy consent to research

A study involving substitute decision makers of people with dementia suggests that proxies (i.e. substitute decision makers) often make decisions based on best interests (e.g. hoping that research will improve the person’s condition or their quality of life) and to a lesser extent on altruism (Sugarman et al. 2001). Several other studies have shown that relatives of chronically ill older people are often not very good at predicting the decision that a person would have made (Alzheimer Europe 2011). This suggests that they are not using an interpretation of will and preferences as a basis for decision making or are not successful in determining what these are. In some cases, relatives and other informal carers may feel under pressure to take on a role that they are not comfortable with. Sugarman et al. (2001) point out that some proxies for dementia research find decision-making responsibility burdensome and that this is

sometimes linked to the degree of risk involved, the extent to which the person with dementia is able to participate in decision making, and the extent to which the proxy or the person with dementia has come to terms with the diagnosis. In keeping with a care ethics approach, it is important to consider the interests of all involved in a particular issue. Whereas the focus is understandably on the person with dementia and on respect for their autonomy, wellbeing and dignity, it is important to consider the rights and wellbeing of the people who are sometimes asked to make decisions on their behalf.

People with dementia may still sometimes be involved without their knowledge, with the approval of a substitute decision maker or on the basis of minimum ability to understand what is involved or having forgotten (either completely or occasionally) having been informed and having consented to it. It is therefore important to ensure that consent is an ongoing process and not merely a one-off signature on a piece of paper. Any such involvement should be ethically justifiable and authorised by an ethics board. An example of such involvement would be for research involving people with advanced dementia who lack the capacity to give informed consent, even with all possible support, who do not show signs of not wanting to be involved and there is reason to believe that they would have agreed to participate had they been able to express a preference. This is entirely different to the use of deception in research, for which there are arguments for and against,<sup>29</sup> and which we are not condoning through our reference to people not being aware that they are participating in research.

### A flexible and inclusive approach to informed consent

New approaches to informed consent are needed, which are more flexible, geared towards the needs of the individual and incorporate elements of shared and supported decision making but also with neutral bodies to decide on individual cases (Alzheimer Europe 2019). This would need to be sufficiently straightforward in terms of procedures, cost and time involved to ensure that the nature of the procedure did not result in further exclusion of people with dementia from research and further restriction of their legal capacity. Whilst cost and effort, as well as the complexity of such an approach, do not provide a justification not to develop or adopt it, it may be more challenging and result in inconsistencies obtaining ethical approval. Any procedure that is excessively bureaucratic, time-consuming or complicated from the perspective of researchers risks the exclusion of the people whose interests it seeks to promote

(by jeopardising their chances of being involved for the reasons mentioned earlier) and this would be unethical.

Traditional competency-based approaches to informed consent to research have been criticised for failing to take adequate account of the situational aspect of capacity and the importance of interdependence and relationships (Dewing 2007). They usually also require a signature which may be difficult for some people with or without dementia. Some researchers have proposed alternative methods based on verbal and behavioural consent. Many people with dementia are able to give informed consent if appropriate adjustments are made and necessary support provided. Process consent is an approach and method to obtain ongoing consent from people “who have an extremely limited capacity, who would generally be thought to be incapable of legally informed consent by others, but on observation can communicate and express their wishes in other ways” (Dewing 2007, p.63). It is a person-centred approach which is also influenced by the concept of social justice and the importance of relationships. Process consent has been implemented, following ethics approval, in the United Kingdom, Ireland and Australia for several qualitative research projects involving people with dementia in the field of gerontology. However, it is doubtful whether it would ever be widely accepted by pharmaceutical companies or ethics boards for participation in clinical trials or for other biomedical research where there are risks of physical harm and fears of people who are considered unable to consent being used for the benefit of others. Such concerns are firmly based on the principle of legal capacity being dependent on decision-making capacity, with various exceptions and adaptations being considered as valid forms of decision making. They may also be linked to fear of litigation.

Dewing (2007) describes the approach as a way to work towards inclusion rather than exclusion of people with dementia in research but recognises that there will still be a cut-off point at which some people will not be able to make or communicate even small choices. Process consent offers an alternative to the current over-emphasis on cognitive capacity, is flexible and focuses on individuals and their residual capacities and other abilities. It is not yet known whether this approach could be further expanded beyond the specific area of gerontological research and there are a few challenges surrounding the observation and interpretation of states of wellbeing. However, Dewing (2007) draws attention to the risk of researchers too readily accepting the gold standard of informed consent and emphasises the need to seek alternative methodologies for consent. The COVID-19 pandemic has resulted in some researchers proposing, and ethics committees accepting, recorded

<sup>29</sup> For more information on this issue, please see section on deception in: [https://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice/2011-Ethics-of-dementia-research/Protecting-the-wellbeing/Recommendations/\(language\)/eng-GB#fragment2](https://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice/2011-Ethics-of-dementia-research/Protecting-the-wellbeing/Recommendations/(language)/eng-GB#fragment2)

telephone consent, the use of electronic/online informed consent forms and online video consent for research involving people with dementia in some countries.

With regard to supported decision making for people with dementia, it is important to ensure that support and relevant materials are also adapted to a broad range of people with dementia (e.g. to people with low levels of literacy,

language skills and education or with additional impairments etc.). People with dementia who are also members of various sub-groups may have experienced additional stigma in the past and be distrustful of figures of authority (Alzheimer Europe 2019). For people with more advanced dementia, there is a risk of conflating difficulties with language and communication with the capacity to consent or to assent to participation in research.

### Recommendations on participation in research

1. Guidelines which serve to exclude complete groups of people from certain types of research should be revised and amended so as to allow individuals who wish to participate in any kind of research the same right to do so as other people.
2. Researchers (and where appropriate ethics boards) should:
  - describe in research protocols the method used to identify a person who could support the patient in the informed consent process, if needed, give details of their plans to seek ongoing informed consent and provide justification if this is not planned
  - allow for the use of simplified information sheets and for information to be presented in a more readable format, like a leaflet
  - ensure that informed consent does not consist of a one-off event if the research is ongoing over a period of time
  - even where a person does not have capacity to consent, be observant of other indicators that the person does not wish to participate in the research (e.g. physically moving away)
  - bear in mind that although a diagnosis of dementia may justify an evaluation of a person's capacity to consent to research, it does not automatically mean that a person lacks such capacity
  - develop and propose to ethics committees alternative and novel methods of obtaining informed consent which are neither exclusionary nor paternalistic (e.g. simplify the process of recording consent such as allowing participants to tick rather than initial boxes on the form)
  - take measures to include people with dementia in the informed consent process, including when they are deemed to lack capacity (e.g. provide information and ask for assent)
  - closely monitor participants during research and check whether they are still willing to participate and understand what participation involves
  - use validated tools, wherever possible and when available, to obtain consent from people from minority groups or with specific characteristics which necessitate special measures
  - translate consent forms for people whose first/best language is not that of the original form, but try to ensure that the translated form is also culturally appropriate
  - be willing and proactive in discussing the issue of shared, supported and substitute decision making with potential participants with dementia and other relevant people
  - ensure that people with dementia are encouraged, where possible, to make their own decisions relating to participation in research, bearing in mind that some may prefer to appoint a substitute decision maker
  - not seek the opinion of a substitute decision maker if the person with dementia has the capacity to decide for themselves.



## Coercive measures

In this section, we look at coercive measures such as seclusion and restraint, which involve restrictions of freedom (to a room, area or building) and the use of various measures to restrict or prevent mobility and movement. Such measures are sometimes justifiable but also risk encroaching on people's human rights as they are applied without a person's consent or despite their protests and may have serious adverse effects ranging from psychological/emotional trauma to physical injury and even death. Coercion is called 'benevolent' if it is performed with the intention of preventing people from harming themselves but there is always a tension between the desire to respect autonomy and the desire to promote wellbeing, which includes protection from harm (German Ethics Council 2018). This does not apply to structural coercion, such as the restrictions imposed on people's everyday lives in care homes and institutions, which limit their choices and are linked to the needs and functioning of the organisations rather than the needs and wellbeing of the residents. This would not be considered as benevolent coercion. The term coercion is often associated with drastic measures and dilemmas linked to autonomy versus paternalism but as Hem, Molewijk and Pedersen (2014) noted in their focus group discussions with Norwegian healthcare personnel, it is also about relationships, communication and cooperation, and the key ethical challenges are often linked to the perception of power and respect.

According to the German Ethics Council (2018) benevolent coercion is similar to paternalism, which also involves overriding a person's will, with the sole or primary aim of protecting a person or their interests from harm. This would be soft paternalism if the perpetrator believed that the person would agree to the act or decision, were they able to make a fully responsible decision, and hard paternalism if the act or decision was in clear contradiction of the person's fully responsible and self-determined will. Fully responsible actions are further defined as being dependent on a person's ability to consent, refuse or choose between different available options, based on an understanding of the intended action (including foreseeable personal consequences and secondary consequences) and the ability to place the decision made in the context of the person's own life vision. The German Ethics Council (2018, p. 10) concludes:

- ▶ *“There is a broad consensus regarding the claim that under certain conditions soft paternalistic acts can be morally legitimate, provided the care recipient is undoubtedly not yet capable, no longer capable, or temporarily or permanently incapable of making a fully responsible decision in the given situation.”*

Whilst the focus of this paper is on the ethical issues linked to the use of coercion, it is worth noting that the whole

rational/justification for the use of coercion, albeit benevolent coercion, rests firmly on the concept of decision-making capacity and is linked to formal and informal legal capacity. The evaluation of decision-making capacity is central to the ethical and/or legal use of coercive measures. In Germany, for example, the Federal Constitutional Court and the German Ethics Council both recognise the legal and moral justification for the use of coercive measures, as a last resort, in certain conditions (German Ethics Council 2018).

This section is divided into four main subsections:

1. formal restrictions of freedom/involuntary placement,
2. informal restrictions/involuntary stay,
3. the use of restraint and
4. restrictions of freedom and the use of restraint during the COVID-19 pandemic.

Some of the issues addressed in a particular subsection will also apply to the others but will not be repeated. We recognise that the terminology used may be different in different countries.

### Formal restrictions of freedom/involuntary placement

Many people with dementia are moved into a residential, nursing or care facility without their consent, even with clear indications of dissent. This is usually but not always the result of a process in a court of law during which they are seen, heard and legally represented. Article 14 of the CRPD states that people with disabilities should “enjoy the right to liberty” and that “if persons with disabilities are deprived of their liberty through any process, they are on an equal basis with others”. As with guardianship measures, legal provisions related to involuntary placement are not yet in line with the requirements of the CRPD as the process of involuntary placement is based on people being denied the right to decide for themselves if they want to move into a residential/care facility. The issue of needing to balance respect for autonomy and dignity with concerns about beneficence and non-maleficence, and discussions surrounding paternalism, are relevant in this context.

The legal justification for restricting the freedom or choice of residence of people with mental disorders is usually that they have a mental disorder and are considered a danger to themselves or others. This is discriminatory because people with no mental illness or disability would not be treated in the same way. Taking the example of a person who is suspected of, or considered likely at some point to commit a terrorist act (i.e. endangering the lives of other people and perhaps taking their own life), they could not be interned on the basis of the mere likelihood of doing harm. It is a common principle in law that a person's freedom cannot be restricted on the grounds that they might

commit a crime but have not yet done so and might never do so. Despite the key difference between being considered likely to intentionally harm others and being in need of care and support, there are in theory alternatives to the involuntary placement of dependent adults but such alternatives (such as a live-in personal assistant/carer for each dependent person) would be expensive and require large numbers of suitably qualified people, which societies at large do not consider feasible.

### *Proportionality and reasonable accommodation*

The concepts of proportionality and reasonable accommodation are related to the issue of freedom of movement and to each other. Proportionality refers to the principle that the least restrictive measure should be considered first. There are competing interests/concerns between respecting the principles of autonomy and beneficence (promoting a person's wellbeing) on the one hand, and respecting the principle of non-maleficence (not doing harm by failing to act in case of danger or unmet needs) on the other hand. Nevertheless, people should not be restricted in their daily lives (e.g. prevented from living alone or going out for a walk) if a less radical measure can be found (e.g. remote monitoring technology and assistive technology, a live-in carer, a home alarm or emergence button on a mobile phone or sheltered accommodation). Such proportionality is linked to the principle of reasonable accommodation because there is usually a less restrictive way of managing a particular situation but it does not always exist as a standard service and usually comes at a price in terms of time, money and effort, as mentioned above.

Governments are ethically and legally required to make reasonable accommodations in keeping with article 2 of the CRPD, which governments in Europe have all signed. This requirement is not, however, absolute as it is stated that it should not entail disproportionate or undue burden and there is no guidance in the CRPD as to what constitutes disproportionate burden (Ferri 2018). There is a risk of prejudice and the devaluation of certain groups of people (e.g. people with dementia, older people and people with disabilities) affecting evaluations of whether certain measures constitute a disproportionate burden (e.g. concluding that the investment needed for such measures could be better used elsewhere and opting for alternative, more 'cost-effective' solutions).

With regard to the principle of non-maleficence, which is about "not doing harm", the WHO definition of health should also be considered. This describes health in terms of physical, mental and social well-being, and not merely the absence of disease or infirmity. Sartorius (2006) argues in favour of an understanding of health based on a balance within oneself and with the environment, whereby people with an impairment or disease are considered as being:

► *"healthy to a level defined by their ability to establish an internal equilibrium that makes them get the most they can from their life despite the presence of disease. Health would thus be a dimension of human existence that remains in existence regardless of the presence of diseases, somewhat like the sky that remains in place even when covered with clouds".*

Discussions about care needs, which may result in potential restrictions of freedom and where there are competing concerns about respecting different ethical principles, risk overly focusing on impairments and diagnoses. They risk giving insufficient attention to social health and, as mentioned earlier, to the right to take certain risks. It would be unethical to restrict a person's freedom by moving them into a residential care home based on concerns about self-neglect or causing a flood or gas explosion (even with their agreement, if it is presented as the only option), if other options had not first been tried. It might, for example, be possible to organise regular and frequent home care assistance or to install smart devices in the person's home.

Every day, people with dementia are uprooted from their communities, lifelong personal and social relationships, separated from pets, regular hobbies and the pleasure of spending time outdoors, and from the security of a familiar environment, and placed in 'safe' environments. Once placed, some find themselves sitting all day alone or with strangers but with a clean bed, a nutritious meal and being safe from physical harm. Whilst some care homes provide opportunities for social contact, which is a positive thing, measures which restrict people's freedom are often disproportionate to people's real needs and personal interests, and could have been avoided if reasonable accommodations had been implemented. Moreover, despite numerous good quality care homes and dedicated staff, others exist in which people are neglected and mistreated, do not have the means to defend their rights and have no contact with those who could have done so on their behalf.

People who are considered as lacking legal capacity may be consulted in decisions about different options but lack the right to insist on one option instead of another. The other parties involved in the decision-making process have different concerns and competing interests:

- Governments need to justify the allocation of resources fairly across different members of society (e.g. children, older people and people with disabilities) and with regard to different areas of life (e.g. health, education, employment or national defence).
- Health and social care departments have budgets which guide what they feel they can offer.
- Informal carers may have competing responsibilities and demands on their time.
- Social care providers may have staffing problems.

These may all impact on discussions about what is considered reasonable. People who have legal capacity and hence rights, rather than mere preferences to be considered, are surely better placed to argue what is reasonable, bearing in mind that the discussion is about their lives and health (physical, mental and social). Supported decision making could be helpful in this respect.

### *The right to community living*

Community-based services are often considered the best approach to the care of older people who require care or support and people with disabilities. Older people and people with disabilities are entitled, according to the Charter of Fundamental Rights of the European Union (2000/C 364/01):

- ▶ *“to lead a life of dignity and independence and to participate in social and cultural life” (article 25 on the rights of the elderly) and*
- ▶ *“to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community” (article 26 the rights of persons with disabilities).”*

People with dementia are nevertheless often moved into residential care facilities against their will and because they do not have the legal right to continue living at home. This may be based on a legal process and be considered as being ‘in their best interests’ or the only solution possible. However, whereas most issues related to restrictions of legal capacity may be linked to decision-making capacity, there is clearly more to involuntary internment than the ability to make a decision and to express one’s will. There are financial issues at stake because enabling a person to remain at home may require a considerable investment in time, effort and money.

In the CRPD, article 19 covers the right to live in the community. It is linked to full inclusion and participation in society and has three key elements, namely choice; individualised support to promote inclusion and prevent isolation, and making services accessible to people with disabilities. According to the Council of Europe Commissioner for Human Rights (2011), “this right is violated

- *when people with disabilities who need some form of support in their everyday lives are required to relinquish living in the community in order to receive that support;*
- *when support is provided in a way that takes away people’s control from their own lives;*
- *when support is altogether withheld, thus confining a person to the margins of the family or society; or*
- *when the burden is placed on people with disabilities to fit into public services and structures rather than these services and structures being designed to accommodate the diversity of the human condition.”*

The reasons for involuntary placement may be expressed in terms of the inability to live independently (e.g. to wash, get food in, keep the home clean etc.) but these are issues that many people achieve to varying degrees. There are scales, assessments and expert opinions but the decisive factors may well be based on value judgements. Taking the example of adoption, in some countries the criteria applied to couples wishing to adopt children would, if applied to the rights of biological parents to bring up their children, result in a massive reduction in biologically-related people living as families. Coming back to decisions about possible involuntary internment, there is a risk of a person’s ability to maintain a clean home becoming an issue, the right to live off baked beans on toast becoming an issue, the right to live like a recluse being questioned and the late payment of bills being considered as a lack of capacity to manage one’s own affairs.

Even if such issues, whilst previously considered one’s own business, can justifiably be considered a welfare and safety issue, there are other potential solutions. The right to legal capacity would and should apply to the right to choose where to live and with whom (alone, with a relative or friend, or in shared accommodation) and it could be argued that ‘allowing’ a person to live in poor or dangerous living conditions would amount to neglect and harm. Respecting legal capacity inevitably challenges the legitimacy of institutionalisation (involuntary placement) and calls for the development of appropriate supported decision making in relation to community living, combined with access to appropriate, affordable and accessible community support services. For this to be possible, commitment is needed from governments and the financial resources to make such support possible.

Meanwhile, guardianship measures still exist in some countries with the effect that guardians (as well as other people) may request an evaluation of a person’s ability to continue living in the community. Once a person has been deprived of the right to live in the community, alone or with others, life in an institution leaves little opportunity for people to express their autonomy in others ways (e.g. deciding when and what to eat, participating in social events in the community, drinking and smoking, choosing when to get up in the morning etc.). The cost of providing appropriate care and support will most probably always be a factor that is raised in discussions about whether and how to enable a person to continue living in the community and as mentioned earlier about what constitutes reasonable accommodation. This raises questions about the perceived value of older people and people with disabilities in society. Do issues about the cost of care and support actually come down to the perceived value of people from these groups? Are there issues about perceived contribution to society, with more value being placed on future rather than past or prolonged contribution? If so,

how does this relate to the recognition and promotion of dignity of people from these groups?

### *Refusal of people with dementia to be assessed for care needs*

In some countries, the necessity for governments to consider possible alternatives before resorting to involuntary placement is enshrined in laws and regulations. However, the possibility to provide the necessary care and support within the person's home or community may be limited by that person's refusal (or that of their carer) to let health and social welfare providers into their home. Decisions to restrict a person's freedom may in some cases be influenced by fear of litigation (e.g. for neglect or non-assistance to a person in danger). Healthcare professionals may, alternatively, be hesitant to intervene in situations where there is little concrete evidence of danger (hence the need for evaluation) but also sometimes to avoid intervening in a difficult situation or to avoid offering services where resources are limited (Mäki-Petäjä-Leinonen 2016). Risks to the person with dementia of not getting timely assessment include malnutrition, self-neglect, dehydration, over-medication, under-medication, abuse and, if the situation deteriorates, loss of the opportunity to continue living at home. Mäki-Petäjä-Leinonen (2016) highlights the difficulty faced by healthcare professionals when the law is not sufficiently clear about this situation and where an exaggerated respect for autonomy may in some cases amount to neglect or abandonment.

Awareness that a system exists, which can deprive a person of their legal capacity and force them to leave their home, may be worrying to people who have been notified of the need for an assessment. If a person had legal capacity and this included the right to stay in their home for as long as they wanted, this would be a neutral situation of

potential benefit to them (i.e. to obtain the necessary support to enable them to do so). A person who has already been deprived of legal capacity (e.g. has a guardian) or fears losing it could quite understandably wish to avoid assessment, particularly as it involves some degree of judgement based on established norms and values. A person may, for example, live off burgers, drink a litre of wine per day and only wash a few times a month. This may be acceptable up to the point that the person's decision-making capacity is challenged, upon which failure to live according to established norms may endanger the right to freedom and risk the loss of legal capacity. Having a diagnosis of dementia may increase the likelihood of the person's decision-making capacity being challenged.

### *Loss of social status*

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 stigmatized. Consequently, people who make this comparison may experience a feeling of injustice, self-stigmatization, shame and loss of social status. Involuntary placement, including being moved into a care home against one's will, involves more than a loss of freedom to choose where one resides. It is also a way of life which can in some cases be dehumanising and fail to respect people's dignity. If people who are 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 wellbeing.<sup>30</sup>

### **Recommendations on formal restrictions of freedom/involuntary placement**

1. Appropriate resources, practices and infrastructure should be provided to enable people with dementia to be cared for in their own homes for as long as is reasonably possible and they so desire.
2. The practice of supported decision making should be promoted in all discussions with the person with dementia about possible restrictions of freedom.
3. In accordance with the principles of subsidiarity and discrimination, services and support should be developed that provide an alternative to involuntary placement in situations where people with dementia have been deemed as lacking legal capacity and as representing a danger to themselves.
4. 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 and wellbeing, in addition to concerns about safety.

<sup>30</sup> See also the subsection on "Self-esteem and humiliation" (p.47).

5. No person with dementia should be detained “in fact but not in law” and thus deprived of the legal safeguards attached to involuntary placement.
6. There should be greater monitoring of how legislation to involuntarily detain people with dementia is used and how this could be amended to reflect a supported decision-making approach.
7. The conditions for the involuntary placement of a person with dementia should not only include proof that they are in danger or at risk if not so detained, but also that alternative less restrictive measures are not possible.
8. People with dementia should be supported during any process for involuntary placement to ensure that alternatives to residential care and other measures of reasonable accommodation have been offered.
9. Before a final decision is made to deprive a person of their freedom, it should be possible for people, if they wish and if it is feasible, to test alternative possible solutions.
10. Steps should be taken to ensure that legislation on involuntary placement is suited to the situation and condition of people with dementia (e.g. not limited to psychiatric institutions or to the possibility of curative treatment).
11. 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, and on the necessity to consider alternative solutions.
12. 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 should have access to independent advocacy.
13. Judges, lawyers and representatives/advocates should be better informed about the social and psychological aspects of dementia and about the nature of capacity and incapacity in relation to dementia, so as to avoid stereotyping affecting their decisions related to involuntary placement.
14. 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 placement resulting from a crisis situation.
15. 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.

### Informal admission to residential care/ involuntary stay

People with dementia are sometimes detained (placed in an establishment) 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. This would be linked to the fact that restrictions being imposed on people who have not been formerly detained would constitute an illegal deprivation of freedom but there may be no one monitoring that and people may not know their rights or how to enforce them.

It is to be hoped that people with dementia are usually admitted into care homes for legitimate reasons (e.g. because they need support and care which can be best or only provided in such homes and without which they would be at risk of harm) and in accordance with legal requirements. However, people with moderate to advanced dementia are at risk of being admitted into care homes without their consent and without any formal legal process

by subtle means. This includes the use of deception such as not telling them that they are moving there by using the guise of respite care or a stay in hospital to disguise the transition, and not responding to requests to go home until they give up or forget they have a home. A typical example would be a person with dementia agreeing to go to nursing home or respite care for a limited time (perhaps linked to a temporary shortage of care or their partner being in hospital) and their requests to go home being ignored or skilfully managed up to the point that they give up, forget or “settle in”, becoming detained in fact but not in law. Psychological or emotional pressure is also sometimes used such as making people feel that they are a burden to others and being unreasonable to insist on remaining in their own home. The use of threat is another way to make a person agree to go into care (e.g. threatening to take a person to court), to deprive them of their legal capacity and to force them to move into a care home. This could provoke feelings of shame, humiliation, fear, loss of control and stigma. There may also be issues reflecting structural discrimination in that appropriate services and support to enable a person to continue living at home might not exist or be affordable.

People with dementia may also sometimes fail to protest against measures to deprive them of their liberty because

they don't realise that they are free to resist or to leave. They may be confused, have difficulty understanding what has happened to them, have difficulty communicating their desire to leave or fear 'making a fuss' and getting on the wrong side of people whom they respect as figures of authority (such as doctors) or fear (based on a relationship of dependency). In the context of day care, lack of voluntariness can also be witnessed through protests to go to day care centres, expressed verbally (and often ignored) or through behaviour such as refusing to get into a vehicle to go there or banging on the door to be let out (often resulting in people being tricked or in the use of physical force).

It is important to bear in mind that coercion is not only about ethical dilemmas linked to autonomy versus paternalism but also about relationships, communication and cooperation. Hem et al. (2014) point out that coercion occurs within the context of relationships and that it is essential for people who are subjected to coercion to feel respected and well taken care of. In the context of involuntary placement, van den Hooff and Goossensen (2013) report the experience of feeling listened to as one of key factors determining whether people feel respected as human beings.

### Recommendations on informal admission to residential care/involuntary stay

1. 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.
2. 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).
3. Procedural safeguards should be developed to protect the rights and wellbeing 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.

## The use of restraint

### Definition and forms of restraint

There are numerous definitions of restraint, which often focus on a particular form of restraint (e.g. physical restraint) or a particular context (e.g. in hospitals or care homes). In this report, we will adopt a broad definition of restraint as being:

- ▶ *“Any method, device, substance, act 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”* (adapted from Alzheimer Europe 2012, p.24).

There are different forms of restraint. Some of the terminology overlaps but the main forms include:

- **Chemical restraint:** the use of drugs/medication to control or change people's behaviour rather than to treat medical symptoms. The intention/purpose is important, in this case, as a drug that 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 appropriate for the treatment of BPSD (behavioural and psychological symptoms of dementia) and does not effectively treat medical symptoms because of the risks and side effects linked to its use.

- **Physical force:** People with dementia are sometimes physically restrained not through devices, equipment or chemicals but by means of hands-on contact. 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.
- **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 achieves 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.

- **Mechanical restraint:** This includes the use of various physical devices such as fixed tables, reclining seats which some people would not be able to get up from without assistance, bed-rails and belts or straps to fix people to chairs and beds.
- **Environmental restraint:** This would cover measures to restrict the freedom of movement of people with dementia by means of adaptations made to the living environment such as complicated locking devices, camouflaging exits, using mirrors, poor lighting, absence of handrails, lack of signposting etc.
- **Psychological restraint:** The use of deception to lead people to believe that they are not free to leave without actually forbidding them to leave. 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 (treating someone like a child), objectification, ignorance and humiliation.
- **Technological restraint:** Assistive technology (AT), especially surveillance and monitoring devices, often receives 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). It has nevertheless 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).

### *Justification for and attitudes towards the use of restraint*

Restraint is currently used across different healthcare settings for some of the frailest and hence most vulnerable members of society (JBI 2002). Its use for people with dementia is rarely justifiable and, if used, should be last resort because research and professional experience has shown that restraint can usually be avoided. However, exceptional circumstances and situations may arise in which the use of restraint could be considered justifiable from a nursing/medical and ethical perspective.

Aside from the issue of whether restraint is ethically and legally justifiable in a particular situation, a common reason given for its use is to protect people from harming themselves, particularly as a result of falling (Karlssoon et al. 2000, Hamers and Huizing 2005). It 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 (see next subsection). 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 wellbeing. Other reasons often cited by healthcare professionals include managing agitation and aggression, controlling behaviour, preventing 'wandering', providing physical support and preventing people from removing dressings and catheters, or otherwise tampering with medical devices (JBI 2002).

Some measures are quite subtle and some people might genuinely use them without really realising that they are in fact forms of restraint. Examples include chairs with fold down/fixed tables, low or tilted chairs that are difficult to get up from, cradle beds, complicated door mechanisms (which are not locked but require a sequence of actions to open them), certain architecture or design, the use of lighting and darkness, some electronic monitoring devices and camouflaged exits. These measures are not measures of restraint *per se* but are sometimes used for that purpose or with that result.

Informal carers may sometimes feel that they have a moral duty to care, or simply care based on a loving relationship with the person with dementia or a sense of solidarity. 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).

It should not be assumed that informal carers who use restraint, do so out of ignorance or a desire to harm someone with dementia. They may sometimes see no possible alternative (e.g. because they need to leave the house or leave the person unattended for a while to buy food, to work or to attend to a child). For many people who are dependent on others for care, their home becomes a prison. At the same time, carers are also entitled to freedom. This can be a difficult balancing act, bearing in mind that there could be a fire whilst a person with dementia is confined to the home or restrained and that someone could choke or fall (as a result of the restraint) within a matter of minutes (Klie 2015). Klie points out that the belief that restraint is the only solution does not make the action legally justifiable and that in Germany, informal carers would be expected to inform guardianship authorities with the aim of obtaining approval for the restraint or obtaining support so as to avoid

the use of restraint. This applies to everyone, regardless of where they live and who is providing or receiving care. Failure to obtain authorisation would render a carer liable to prosecution. In many countries in Europe, however, such support would not be available and informal carers would still be faced with an ethical dilemma.

In the context of professional care, restraint is often used because of understaffing, lack of competent staff, the desire for peace and quiet for residents or staff, and lack of knowledge about alternatives to restraint and about the consequences of using restraint (Hantikainen 1998, Kirkevold and Engedal 2004, Gastmans and Milisen 2006). 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 on the use of physical restraint may explain why it is not always reported or reasons given for its use.

There are different tiers of responsibility within care establishments, namely the responsibility of legislative authorities and health care systems, the responsibility of various institutions or homes, personal responsibility and responsibility as a member of a team, and that professional carers often find their range of options for action somewhat restricted (German Ethics Council 2018). There are often 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 in some care homes, thereby making it difficult for staff not to use them as it would mean going against the hierarchy. This can be considered as an 'instruction to discriminate' whereby staff are obliged to act in a discriminatory way. Some homes may simply turn a blind eye to various practices in the interests of efficiency and cost saving.

Newerla (2017) suggests that acute care establishments such as hospitals are primarily driven and motivated by economic concerns and that people with dementia are often perceived as threatening or disrupting established routines and the bureaucratic/economic functioning of such organisations. People with dementia are often experienced as unpredictable and disruptive, failing to comply with the long-established power relations and the mantra that everything can be managed. They come to be seen as 'the problem' and are transformed into 'docile bodies' by means of sedation (Newerla 2017, p.197). Professional carers become entangled in the system, caught between what they feel they have to do and what they know and feel

they should do, with little or no freedom for manoeuvre. This sometimes takes a toll on their physical and emotional wellbeing. Newerla (2017) argues in favour of training and increased awareness about dementia amongst care professionals but recognises that the ability to provide holistic care and to look for flexible and creative solutions (e.g. to avoid the use of restraint) can be hampered by the care ethos, and by economic and structural constraints of organisations.

The reasons and situations described above should not be interpreted as justifications for the use of restraint. They simply 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 and reflects their wishes, 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 carers, are in a vulnerable position. The onus is therefore on informal and professional carers to respect people with dementia and to act ethically towards them.

Problematic situations are not caused solely by people with dementia. They are also 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 and why?"

### *The negative impact of 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, mobility/agility and actual death. Examples are provided below:

- Medical/physical consequences include bruising, acute functional decline, decreased peripheral circulation, cardiovascular stress, bladder and bowel incontinence, constipation, muscle atrophy, pressure ulcers, nerve damage, infections, asphyxiation, strangulation, cardiac arrest and even death (Evans et al. 2002, JBI 2002, Cotter 2005, Cotter and Evans undated, Gastmans and Milisen 2006). 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 2006). 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 victimisation, 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 (Evans, Wood and Lambert 2003, Cotter 2005, Hamers and Huizing 2005). Chemical restraint can also result in changes in someone's personality, which may have a knock-on effect on a person's relationships with others.
- Consequences linked to mobility and agility include decreased muscle strength and balance, decreased mobility, increased risk of falls and injury, even resulting in death (see below) (Tinetti, Liu and Ginter 1992, Capezuti et al. 2002, Evans et al. 2002). 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. People may fall as a result of struggling over barriers (such as bed rails) or as a result of fatigue or unsteadiness following an effort to free themselves from a restrictive measure (Cotter 2005).
- The use of various forms of restraint, such as mechanical, physical and chemical restraint, can sometimes result in death. An analysis of 26 deaths occurring whilst people were being physically restrained in Munich between 1997 and 2010 revealed three natural causes, one suicide, 11 cases of strangulation, 8 cases of chest compression and 3 cases of dangling in a head-down position (Berlanovich, Schöpfer and Keil 2012). Cotter (2005) draws attention to the risk of people who have been physically restrained becoming trapped between the headrest, mattress and bed rail which can lead to asphyxiation and strangulation. With regard to chemical restraint, Banerjee (2009) assessed the risks and benefits of using antipsychotics for people with dementia and concluded:
  - ▶ *"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 assumption 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"* (Banerjee 2009, p.28).

### *Self-esteem and humiliation*

Being subjected to restraint can be humiliating. There are two key concepts linked to the potential humiliating effect of loss of freedom of movement through the use of restraint, namely people being treated as if they were objects or sub-human, and the experience of loss of control (which lies at the very centre of legal capacity).

According to Avishai Margalit (1996), a decent or civilised society is one whose institutions do not humiliate people under their authority and whose citizens do not humiliate one another. Humiliation is described as:

- ▶ *"any sort of behaviour or condition that constitutes a sound reason for a person to consider his or her self-respect injured"* (1996, p. 9).

It can only result from the acts or omissions of humans (i.e. not solely as a result of having a certain condition). Although humiliation cannot occur in the absence of humiliators, it may occur without the humiliators necessarily having intended to humiliate a person. A decent society is further defined as one that fights conditions which constitute a justification for its dependents to consider themselves humiliated. In the case of dementia, the sound reason might not necessarily be the result of logical reasoning and people with dementia might not necessarily be able to communicate their sense of humiliation but such humiliation may nevertheless be sensed and experienced. In the context of involuntary internment and the use of coercion, there are acts and omissions on the part of individuals, institutions and governments that are likely to result in people with dementia having sound reason to consider their self-respect injured.

People are sometimes being described as empty shells, zombies, having no mind and no longer being the person they used to be (Alzheimer Europe 2013) and treated like objects. This can be linked to stigmatization whereby people are identified as having a certain socially salient characteristic that is labelled, negatively stereotyped and devalued, leading to negative emotional reactions towards them and discrimination (Link and Phelan 2001). Stigmatization always occurs in the context of unequal power relations. Loss of legal capacity involves a considerable loss of power and in situations where restraint and coercion are used, the power imbalance is particularly clear.

It is, however, important to distinguish between treating humans as if they were objects and treating them as objects. It is unlikely that people are really perceived as things. It would be quite pathological to genuinely believe that a person was no longer a person (although this may be the case for some people vis-à-vis others in a persistent vegetative state). It is about perceiving the human aspect in a human being. Margalit (1996) gives the example of servants

of wealthy people who choose not to 'see' them and in a way to treat them as if they were objects, and for the servants to render themselves as inconspicuous as possible, to act as if they were minding their own limited business and ignoring everything else so that their masters can overlook them with ease. Seeing a person as human and looking at people 'in detail', according to Margalit, means looking beyond the physical body parts - a kind of psychological perception such as seeing worried eyes, kind eyes or bored eyes. Such perception might not always be accurate but when someone sees someone as human, they cannot see that person otherwise. Failure to recognise or acknowledge personhood and human status is an extreme form of devaluation within the process of stigmatization (Goffman 1963). Narchi and Ritzi (2019) suggest that people find it easy to justify the use of restraint when, instead of seeing people with dementia as having dignity, they perceive them as heavily damaged organisms.

According to Margalit, people cannot directly control what they see but can try to change their way of looking at people and develop "a-stigmatic" vision (i.e. to ignore stigmata and to see people precisely in their human aspect). This way of seeing is a combination of perception and thought. Thich Nhat Hanh describes this as looking beyond labels and recognising that labels are not reality.

► *"We must train ourselves to look at each other beyond labels, and to see our true nature"* (Nhat Hanh 2019, p.70).

People who are obliged in the course of their professional duty to use restraint or coercion on people with dementia may face an ethical dilemma. Those who are subjected to restraint or coercion may feel that they are being treated as objects or as subhuman and thereby have sound grounds to consider their self-respect injured even in cases where they are not perceived in that way or where those carrying out the act or omission felt that they had no alternative.

The other aspect of humiliation is loss of control, consisting of the deliberate infliction of utter loss of freedom and control over one's vital interests, and, subsequently, rejection from humanity. The humiliation goes beyond the cruelty of confinement or restriction. It is symbolic of subordination - of being denied the equal right to exercise choice and protect one's very existence. This constitutes an existential threat. The perpetrator, especially if an institution, has power over victims who feel helpless and unable to protect their vital interests. In the case of restraint, such helplessness may be linked to the loss of legal capacity, informal regulations and/or the physical, mechanical, technological or other restrictive measures adopted. In rare situations where the use of restraint or coercion may be ethically and legally justifiable and applied with consideration and respect, the person with dementia may nevertheless be unable to understand and consequently feel humiliated and experience existential threat.

### *Dignity, freedom and embodiment*

As a philosophical discipline, "phenomenology is the study of 'phenomena': appearances of things, or things as they appear in our experience, [...] thus the meanings things have in our experience" (Smith 2018). Like other disciplines, phenomenology in the 20<sup>th</sup> and 21<sup>st</sup> centuries experienced the so-called "body turn" or "corporeal turn", involving a paradigm shift towards the study of corporeal aspects of human experience (Alloa 2012). With regard to the human body, phenomenology applies the following distinction: Firstly, the body appears as a three-dimensional object among other objects. It is merely an objective body that can be called 'corpus' in Latin and 'Körper' in German. Secondly, the body can also be the means through which the world appears to us and through which we enact our freedom. For this phenomenon the German term 'Leib' can be used. In the absence of a direct translation, Leib could be paraphrased as 'embodiment' or 'living body' (Coors 2020). In French phenomenology, terms like 'la chair', 'le corps vivant' and 'le corps mien' have been proposed. Encompassing both objective and subjective aspects, embodiment focuses on the psychophysical unity that is the human living body.

Reflecting this corporeal turn, recent scholarship has introduced the observations of the phenomenology of embodiment into the discourse on measures of restraint especially in older people with dementia (Ritzi and Kruse 2019). The restraint of a human being's freedom does not take place in an invisible realm of ideas but directly concerns the psychophysical unity of the living body. Indeed, from a phenomenological perspective, it can be argued that human dignity and human freedom directly appear and manifest themselves in a bodily manner. The living body is the possibility and to a large extent the realisation of a human being's personal freedom. A person realises themselves through their embodiment (Fuchs 2008).

Fuchs (2008) also notes that throughout life, a person has bodily experiences with the world and that these experiences are reflected in bodily habits over time, which can be called embodied cognition ('Leibgedächtnis'): Automatic sequences of movements, well-rehearsed habits, the skilful use of instruments etc. Here, a part of the person's memory and biography has become, so to speak, flesh and blood and, interestingly enough, remains there for a long time even in dementia. Thus, it can happen that the biography of a person with advanced dementia no longer expresses itself verbally, but still in a bodily manner - reflecting what Kruse (2017, p. 337) calls 'islands of the self' ('Inseln des Selbst').

On an even more fundamental level, with regard to human freedom and freedom restraining measures, it can be stated that it is not only the biography of a person that manifests itself in a bodily manner. Rather, as stated above, it is the freedom of the human being that manifests itself through embodiment. Thus, through realising freedom the living

body is also the expression and manifestation of human dignity. Indeed, it would be wrong to say that physical or mental violence only harms the body of a person and not the person themselves. A violation of dignity can concretely express itself in the bodily humiliation of the human being (see also previous subsection on Self-esteem and humiliation, p.47). The abstract dignity and freedom of a person is violated and restricted concretely in their body. This applies especially to measures of restraint (Ritzi and Kruse 2019).

While this is immediately obvious in the case of fixations that are close to the body and other (e.g. spatial) precautions, it should be explicitly pointed out that also, and especially when administering psychotropic drugs, an intervention in the 'sovereignty of the living body' occurs. This is particularly problematic, ethically speaking, when these drugs are administered with the mere aim of sedation (i.e. as a form of chemical restraint). The concept of embodiment makes the severity of such interventions clear. Hence, Ritzi and Kruse (2019) show that drug sedation may appear peaceful and gentle from the outside, but that there is a more serious interference with the person's living body, since this measure penetrates into the interior of human beings and deprives them of the possibility to freely control their bodies. They conclude that measures of restraint intervene in the bodily manifest freedom of the person and represent a form of humiliation and violation of bodily sovereignty. Alternative measures must always be exhausted.<sup>31</sup>

### *Respect for autonomy*

The issue of autonomy with regard to the use of restraint and coercion is not solely about being deprived of the freedom to decide what to do or not do, with whom and how. The initial loss of freedom of choice is 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 a particular 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.

If restraint is only ever used in exceptional circumstances and as a last resort, this means that alternative solutions are found or that the person concerned eventually agrees to the proposed intervention. Part of the process of avoiding coercion is therefore to seek the person's informed consent and to provide the person with the necessary support to make an informed decision. However, if the person knows that the measure will be applied regardless of whether they consent or not, and if the methods of persuasion are not respectful of that person's dignity, such consent if eventually given (perhaps reluctantly or without full conviction) would be meaningless, a mere formality resulting from some degree of coercion (German Ethics Council 2018).

### *Security versus well-being*

In rare cases, it might be ethical to use restraint but there is always a risk that its initial use is continued thereafter, when there are no longer grounds to justify its use. Restraint is often justified on the grounds that it is necessary to prevent a person from coming to harm (e.g. when there is no time to investigate possible causes for the behaviour or to try other options). We have already argued that far from preventing harm, restraint may actually lead to accidents and even death. We have also considered, earlier in this report, 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 wellbeing, especially when it concerns other people who are considered as vulnerable and for whom someone is responsible.

There is a risk, when defining whole groups of people (such as people with dementia) as vulnerable, of restricting their legal capacity irrespective of their actual needs or capacities, based on stereotypes and assumptions. The CRPD Committee has described this as discrimination on the basis of perceived disability (Waddington and Broderick 2018). This typically occurs when people with dementia are characterised on the basis of the stereotype of advanced dementia

<sup>31</sup> See subsection on Measures and approaches to avoid the perceived need for or actual use of restraint.

and blanket 'protective' (restrictive) measures are applied to people who don't need them.

It may be considered acceptable for people to engage in acrobatics and mountaineering, even to surf in shark-infested water, 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 stretch her legs, chat with other residents, make a coffee or go to the toilet. The refusal of this right, whether based on a formal or informal restriction of capacity, may in the long run have far-reaching effects such as social isolation, depression, premature loss of mobility, poor physical health, not feeling 'at home' and functional incontinence. It may result in feelings of shame and humiliation, which touch on issues of dignity and personhood. 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 wellbeing.

Goethals et al. (2012) reviewed qualitative literature on nurses' decision-making in the case of physical restraint. Concerning the issue of security and wellbeing, they point out that nurses' decisions to use physical restraint are 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 the wellbeing of staff and all residents/patients in their care. 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 wellbeing, 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). The use of restraint may also damage the relationship of trust between people with dementia and professional carers.

### *Measures and approaches to avoid the perceived need for or actual use of restraint*

Various forms of assistive technology, as well as approaches, procedures and attitudes, may help prevent the perceived or otherwise justified need to use restraint on people with dementia. Narchi and Ritzi (2019) provide examples of devices and equipment such as low/floor beds, crash mats, non-slip mattresses and stocks, sensory mattresses, light switches and other detectors, alarm systems, hip protectors, helmets, easy walkers (walking support with inbuilt seat) and various mobility aids. They also draw attention to practices and the environment or design of buildings such as maintaining mobility, adequate lighting, removal of obstacles which might lead to falls, speedy response to calls for assistance, biography work, cooperation with informal carers, attention to people's needs and wishes, continence management, assistance with communication, structured activities and respectful interaction.

Referring to Kant's famous question, "What should I do?", Narchi and Ritzi suggest that in the context of decisions surrounding the use of restraint, this could be formulated as follows:

► *"What should I do in this specific [acute hospital] care situation, which it seems can only be resolved through the use of restraint"* (2019, p. 275).

The German Ethics Council describes four criteria to be respected in cases where restraint is believed to be morally and legally justified. These are:

1. The means of restraint must be suited to the goal, and should be necessary and proportionate.
2. The protection from harm must not be disproportionate in the sense that it risks causing other irreversible damage.
3. The risk of harm cannot be avoided by other less extreme measures.
4. Consent should be sought if the person for whom restraint is considered necessary is capable of making an autonomous decision.

Narchi and Ritzi (2019) propose further key questions or points that carers could ask themselves and reflect on so as to ensure that these criteria are indeed met. Please see Appendix 3.

## Recommendations on the use of restraint

### For government, policymakers and service providers

1. Policymakers and service providers should strive to provide the least-restrictive environment for people with dementia in need of care, support or treatment.
2. The allocation of resources at all levels should reflect the commitment to achieving the least restrictive environments for care, support and treatment.
3. An awareness-raising campaign should be developed to inform people about the relevant legal and ethical issues linked to the use of restraint.
4. A legal framework and guidelines should be developed to protect people with dementia from the unjustifiable use of restraint.
5. The use of restraint on people with dementia should be considered as unethical and a form of abuse unless justification can be provided to prove the contrary.
6. 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 professionals can report their concerns anonymously.
7. This organisation should be granted the power to make unannounced inspections, to issue recommendations to organisations to change their practices and to take appropriate legal action if necessary.
8. Governments should set targets to reduce the prescription of antipsychotic medication for people with dementia.
9. Regular medication reviews should be required to help prevent doctors simply switching to alternative medication (i.e. to replace one antipsychotic drug with another type of medication that has a similar effect).
10. Clear guidelines should be developed for doctors and nurses on the prescription and use of antipsychotic medication for people with dementia, covering the dangers of such medication and the need to reduce such prescriptions.
11. Doctors, nurses and care staff should be provided with training on alternatives to using medication to treat BPSD (e.g. the use of psychosocial interventions).
12. Training should be provided to help doctors, nurses and care staff understand the factors that might contribute to BPSD (e.g. a noisy environment, anxiety, pain and frustration) and how to mitigate them.
13. 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 their transferral 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

1. 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 and as a last resort, unless there is no time or it would be too risky to attempt another approach.
2. Such situations are considered extremely rare and should be avoided by careful general planning and reflection.
3. Before restraint is used on people with dementia all other less invasive means must have been tried.
4. If ever justifiably used, restraint should be applied with particular attention to the person's psychological and emotional wellbeing, and in a respectful manner which communicates recognition of a person's value, dignity and need to feel protected from harm. Even if necessary, proportionate and justifiable, it may still be experienced as traumatic.
5. The expected benefit of the restraint used must significantly outweigh the likely harm to the person concerned, including humiliation, existential fear and loss of dignity, self-respect and trust.
6. Whilst guidelines may be helpful, a person's wellbeing or welfare should not be determined in the abstract or with regard to the interests of third parties, but must be based on each person's individual circumstances and point of view, including their biography, history and cultural background.
7. 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. In some cases, this may not be feasible because of the urgency of the situation but should take place as soon as possible afterwards.
8. Restraint should not be used without the consent of a person's legal representative/guardian, if there is one.

9. The person who is restrained should be involved as far as possible in decisions regarding the actual implementation of the measure.
10. The reason for the restraint and its likely duration should be discussed with the person concerned, who should be treated with compassion and made to feel safe.
11. Cultural and linguistic barriers should be addressed. If necessary, interpreters should be involved and cultural and religious needs considered. This necessitates intercultural awareness, sensitivity and competence.
12. In most cases, the use of restraint should not be considered an option but rather a failure to provide good care (which may not always be the fault of the carers but rather that of a care organisation).
13. Restraint should be used for the shortest time possible and the restrained person should not be left unattended.
14. Restraint should never be used on a routine basis even if initially prescribed by a doctor.
15. Before considering how to deal with BPSD and challenging behaviour, it should be determined for whom such symptoms and behaviour are disturbing.
16. Judicial approval should be obtained for the use of any form of restraint. If necessary (e.g. in emergency situations) this should be obtained retrospectively.
17. Any use of restraint should be documented.

#### **For professional caregivers**

1. Care homes should:
  - have a clear policy about not using restraint
  - develop and implement a policy of zero tolerance of restraint (subject to rare exceptions)
  - support and provide care home staff with alternative means to enable them to provide restraint-free care, including environmental changes, activities, care and nursing procedures, medical and psychosocial approaches, safety equipment, the use of assistive technology and awareness raising about dementia (see JBI 2002 for examples)
  - investigate any use of restraint that may have occurred in an exceptional situation to determine whether there was any alternative, whether judicial approval was sought, even retrospectively, and how a similar situation could be avoided in the future
  - ensure that measures of restraint are not readily available to personnel who provide care or treatment to people with dementia
  - ensure that the demands of the organisation with regard to the provision of care do not encourage care staff to restrain residents
  - 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
  - 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.
2. Doctors and health and social care professionals should:
  - receive training in the use of non-pharmacological interventions to deal with behavioural and psychological symptoms of dementia (BPSD) and challenging behaviour
  - be informed about the risks involved in using restraint on older people and people with dementia
  - receive training on how to reflect on the ethical issues linked to the use of restraint
  - be informed about the ethical and legal implications linked to the provision of care as well as to the use of restraint
  - ensure that when psychotropic medication is administered on a PRN basis, the reason for administering it at a given time is documented and regularly reviewed
  - record all use of restraint (e.g. type, duration and reason), as well as measures taken to reduce its incidence
  - be knowledgeable about alternatives to the use of restraint
  - if restraint is needed and justifiable, be knowledgeable about milder forms of restraint that could be tried first
  - have access to alternatives to the use of restraint
  - conduct case discussions with all involved actors before any use of restraint. These case discussions should take into account the life rhythm and biography of the person with dementia.
3. With regard to psychotropic medications doctors should:

- be obliged to justify that any prescription of psychotropic medication is appropriate, effective, clinically justifiable and proportionate to the perceived need
- ensure that any prescription of psychotropic medication is time limited and regularly reviewed.
- consider whether BPSD and challenging behaviour are caused by other factors which might require specific treatment or non-pharmacological approaches
- never prescribe psychotropic medication to be administered on a routine basis
- ensure that the potential benefits outweigh the risks for each person receiving them and be able to justify this
- reassess the appropriateness of the prescription for any person with dementia already taking antipsychotic medication should be reassessed
- not simply replace the use of psychotropic medication (i.e. in accordance with recommendations to reduce this practice) with other types of medication serving the same purpose (i.e. using alternative medication as a means of restraint).

#### For informal carers

1. Informal carers should:
  - be informed about the legal and ethical issues linked to the use of restraint
  - be provided with training to deal with BPSD and behaviour which they may find challenging
  - 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
  - know about and have access to alternatives to the use of restraint.

## Restrictions of freedom and the use of restraint during the COVID-19 pandemic

### *Impact of measures adopted during the COVID-19 pandemic*

During the COVID-19 pandemic, some people with dementia living in residential care or nursing home settings have had their freedom restricted, often accompanied by a total restriction on visits from relatives, friends and guardians. Others have been asked to self-isolate or cocoon, and for friends and family to stay away. Lockdown measures have further exacerbated the social exclusion and isolation of many people with dementia. In some countries, large numbers of people living in care homes have been deprived of access to intensive care treatment and others discharged from hospital without having been tested for the coronavirus, and moved back into residential care settings, thereby potentially endangering the lives of co-residents. There have also been reports about the blanket application of DNARs (do not attempt resuscitation orders) being placed on residents in care homes.<sup>32</sup> Emergency measures have been introduced via emergency legislation in several countries, in some cases simplifying and speeding up assessments, overriding the need to see and hear people directly and eliminating the necessity to involve substitute decision makers in the process for involuntary placement.

Such measures, although intended to be temporary, may have a devastating and long-lasting impact on people's lives, leading to emotional and psychological suffering and a deterioration in physical, cognitive and mental health. Many people with dementia have died during confinement or as a result of contracting the virus from residents or even staff (from whom they had no possibility to distance themselves and who often were not aware that they had the virus themselves due to lack of testing). Measures adopted during the coronavirus pandemic, which is still ongoing, have also had disastrous effects on families and close friends of people with dementia. The full consequences of COVID-19 measures are not yet known and at the time of writing this report it is not known how the distribution of a possible vaccine will affect people with dementia.

Two main justifications for restrictions of freedom have been put forward. The first is to protect vulnerable people in keeping with the ethical principles of beneficence and non-maleficence. However, this is not very convincing in the light of the lack of precautions in many homes to protect people with dementia (e.g. staff having no or insufficient protective clothing and materials, staff and residents not having access to testing and in some cases, residents being denied access to hospital treatment and others being released back into the home without prior testing). The Fundamental Rights Agency estimates that by the

<sup>32</sup> See also section on Treatment, care and support.

end of May 2020, testing of care home residents and staff was only planned or underway in a third of EU countries. In many countries, protective clothing has been scarce or inadequate, even in government-run establishments, and the situation for private care companies has often been even worse. A report by the Swedish Corona Commission on care of older people during the pandemic concluded that:

- ▶ *“the absence of clear guidelines and lack of PPE in LTC [long-term care] settings contributed to the spread of the virus. It took unreasonably long to clarify and define the need for PPE in LTC, there were no channels to report needs or organise delivery”.*

Residents in some homes would clearly have been safer in their own homes or for those who have relatives, living with them. There have been several accounts in the media of families fighting, often unsuccessfully, for the release of their relatives from care homes. Others have no relatives able to care for them at home and few if any visits, and are forced to live in an environment in which they sometimes have no opportunity to protect themselves from harm.

The second justification is linked to the declared need to protect national health systems from becoming overloaded and unable to function. This seems to favour the protection of a system over the protection of the needs, wellbeing and lives of a particular group of real people, although clearly, a total breakdown of a health care system would result in no one's needs being met. The justification could nevertheless be considered as discriminatory in that keeping older people out of hospitals so as to free up beds for others (i.e. younger people or people without dementia) results in two different levels of care; one for care home residents (including many people with dementia) and one for other people, with the former often receiving a lower standard of care (e.g. because of the lack of availability of medical specialists, life-saving and sustaining medical equipment and a sterilised environment). We will come back to the issue of discrimination later in this section. The justification is also flawed in that thousands of people died in care homes whilst huge newly constructed or transformed hospitals lay empty (e.g. in England) and numerous essential and elective treatments were cancelled or postponed. The number of people consulting doctors and emergency departments decreased dramatically, which means that thousands of people have missed out on the detection and treatment of serious illnesses.

Across Europe, the number of deaths in each country has been calculated in different ways and in some countries, the statistics only covered people who died from coronavirus in hospital. People who died at home or in care homes did not ‘count’ and the scale of the potential neglect of some groups of people is not known. As many people who died within the community were not tested for coronavirus, this

was also not recorded on their death certificates, thereby overlooking many people with dementia, especially in care homes, who most likely did die of coronavirus. Vital proof that might reveal that measures were not successful in protecting them from harm is therefore lacking.

### *Were measures taken justifiable?*

Most members of society can choose whether to comply with various measures, such as distancing, self-isolating and wearing face masks and in some cases to face penalties for failure to comply with such measures. People with dementia in care homes or who are dependent on others for care and support often lack that same freedom and decisions are more or less imposed on them. Regulations and procedures within care homes could be seen as constituting an informal loss of legal capacity whereby residents are denied the right to make their own decisions with regard to matters concerning their daily lives. During the pandemic, the measures they are subjected to in some countries (e.g. confinement, distancing, loss of family life and restricted access to essential treatment) are imposed by governments and involve a mass loss of legal capacity of potentially vulnerable groups. This is in no way linked to decision-making capacity or amenable to deviations from procedure in relation to support that could be provided by family and friends. This observation is about approaches adopted by governments and does not reflect a criticism of the many health and social care professionals who have struggled to provide appropriate and timely treatment, support and care to people with dementia and informal carers despite fears for their own safety, and that of their families, and increased workloads resulting from reduced levels of staff. Some health and social care professionals have lost their lives as a result of continuing to provide care.

As mentioned in the introduction to this report, there is often a close relationship between law and ethics. There is often an assumption that laws should be ethical, and people therefore often question whether that is the case. In the Universal Declaration of Human Rights (1948), there are articles covering the right to life, liberty and security of person (article 3), not to be subjected to torture or to cruel, inhuman or degrading treatment or punishment (article 5), to be recognised everywhere as a person before the law (article 6), to protection against discrimination (article 7), not to be subjected to arbitrary arrest, detention or exile (article 9) and not to be subjected to arbitrary interference with his privacy, family, home or correspondence (article 12), to name but a few. However, according to the United Nations Human Rights Office of the High Commissioner Covid-19 response (2020, p.1),

- ▶ *“Even without formally declaring states of emergency, States can adopt exceptional measures to protect public health that may restrict certain human rights.*



*These restrictions must meet the requirements of legality, necessity and proportionality, and be non-discriminatory.”*

The WHO points out<sup>33</sup> that quarantine and other restrictions of freedom must always be part of a comprehensive package of public health and social measures, should fully respect people’s dignity, human rights and fundamental freedoms, should be in accordance with the law, pursue a legitimate aim, be proportionate and not arbitrary or discriminatory.

According to Ireland’s Ethical Framework for Decision-Making in a Pandemic (Department of Health 2020), legitimate restrictions of an individual’s freedom can be justified:

- in cases where exercising that freedom places other people at risk,
- where best available scientific evidence indicates that such measures will achieve the intended goal,
- provide that the measure is proportionate to the anticipated benefit,
- provided that no less restrictive measure would be effective and that failure to implement that measure would result in significant harm,
- provided that the measures do not involve unfair discrimination,
- provided that the people whose liberty is restricted in order to protect others are given extra support and well looked after.

The emphasis of the above is on restrictions of liberty being for the protection of other people and on restricted people being well cared for. This has not always been the case for many people with dementia (and older people) in care homes who might have benefited more from other members of society having their freedom restricted in the same radical way. A key issue is perhaps that of the collective good and public health goals, whereby the emphasis is put on protecting the healthcare system, which serves the whole population, with certain groups of people being labelled as jeopardising it as a result of their particular vulnerability (discussed later).

### *Factors affecting the justifiability of restrictions of freedom*

#### **Legality**

Recently, some relatives of people with dementia in care homes who have been denied the right to visit have argued that the rights of people with dementia to family life and to

receive visits are being denied and that consequently, their fundamental rights are not being respected. The pertinent provision relating to the right to family life lies in Article 16(3) of the Universal Declaration of Human Rights,<sup>34</sup> which states:

► *“The family is the natural and fundamental group unit of society and is entitled to protection by society and the State.”*

In keeping with recent cases in the European Court on Human Rights, family life is a broad concept covering a range of personal ties involving people living together and the existence of close personal ties, regardless of the marital status of the people concerned (ECHR 2020). During the pandemic, partners (some having been together for decades), their children and other members of their families have been denied all direct, physical contact or presence. The loss of contact with relatives and close friends may be a factor contributing towards a further, in many cases serious, deterioration of the condition of people with dementia. In keeping with the concept of health as also incorporating social health, the losses experienced by people with dementia confined within residential care settings may be disproportionately high.

Although, as explained earlier, governments have the right to introduce certain restrictions to protect public health, in its paper Ethics & COVID-19 – Restrictive Measures and Social Distancing (March 2020), the WHO insists on the necessity for oversight and accountability mechanisms to be in place to allow people who are impacted by public health restrictions to challenge the appropriateness of those restrictions. Appropriateness is further linked to the issue of discrimination as it is also stated in numerous national, European and international texts that discrimination is prohibited on a range of different grounds such as race, colour, sex, sexual orientation and gender identity, disability, language, religion, political or other opinion, national or social origin, property, birth or other status. For people with dementia, whose legal capacity is being formally or informally restricted through the imposition of such measures, the opportunity for them or their relatives and friends to challenge the legality of these measures is somewhat limited, and likely to become more so as time passes. Retrospective challenges are likely to be even more difficult.

#### **Necessity**

There is usually more than one possible approach to take, especially in catastrophic situations for which the future development is unknown. Many governments across Europe

<sup>33</sup> With reference to Article 3 of the International Health Regulations (2005), UN Committee on Economic, Social and Cultural Rights General Comment 14 (2000), the International Covenant on Civil and Political Rights (ICCPR) (1976) and the Siracusa Principles (1984).

<sup>34</sup> Also in Article 23 of the International Covenant on Civil and Political Rights, and Article 8 of the European Convention on Human Rights.

have claimed that their decisions to adopt certain measures were necessary (i.e. to control the virus and thereby protect the healthcare system and/or vulnerable populations) based on 'scientific evidence' but have nevertheless relied on different research or drawn different conclusions from research findings. Despite close collaboration with researchers, the actual decision makers tend to be politicians with responsibilities not only for the health of their citizens, but also for economic and political stability. It was and is still not known how the situation will progress and Fritz et al. (2020) suggest, with regard to claims about 'following science', that:

- ▶ *"... this implies that the science alone will tell us what to do. Not only does this rhetoric shift the responsibility for difficult decisions on to "the science", it is also wrong. Science may provide evidence on which to base decisions, but our values will determine what we do with that evidence and how we select the evidence to use. It is disingenuous and misleading to imply that value-free science leads the way. Both science and policy are value laden."*

Consequently, decisions taken about necessary action during the pandemic, which may have a huge impact on people's lives, especially on potentially vulnerable populations, represent a perspective of what is necessary resulting from a specific interpretation of the results of scientific studies, not on 'facts' alone. It is essential for governments to be open about this, not to hide behind science or select the science to suit the decision.

### Proportionality

There has been some discussion in the media about whether measures introduced during the pandemic were disproportionate in terms of their impact and burden on older people and people with dementia. The principle of proportionality means that approaches adopting, during the coronavirus in this case, should be proportional to the good that may be achieved and any harm that might be caused. Protective measures (i.e. to protect public health or health care systems) resulting in restrictions of freedom of whole groups (e.g. people with dementia living in care homes, people over 70 etc.) which cannot reasonably be monitored or challenged at the individual level, may result in disproportionate suffering compared to potential gain at the individual or societal level. If measures are not accompanied by adequate health and safety provisions for those whose freedom has been restricted, they should be considered unethical even if, technically speaking, legally justifiable during public health threats. At the level of society and in keeping with a utilitarian approach, whereby a particular action is ethical if

it produces the greatest good for the greatest number, it is still difficult to justify some of the measures adopted.

Another approach could have been to focus on protecting the health of those members of society who are most vulnerable by allocating most resources to their protection (e.g. testing, protective gear and access to intensive care treatment), in recognition of interdependency and the equal value of all human beings. Statistics on people dying from COVID-19 in residential care facilities provide some indication of the disproportionate nature of COVID-19 measures for groups of people which typically include a high percentage of people with dementia. In France, for example, almost 7,500 care home residents died of COVID-19 and this represented a third of all COVID-19 deaths.<sup>35</sup> Alzheimer Scotland has called on the Scottish Government:

- ▶ *"to take urgent action to understand the reasons why people with dementia are disproportionately represented in the deaths from coronavirus and the excess deaths during this pandemic"* (Alzheimer Scotland 2020, p.19).

Dementia is typically accompanied by difficulties with language and communication. Relatives and close friends contribute towards maintaining the psychological and emotional wellbeing of people with dementia. They also often play an important role in helping residents to communicate their needs, concerns and preferences to staff. Lockdowns and distancing measures make this difficult, if not impossible. Because of the lockdown and no outsiders seeing what goes on in people's own homes and in residential care settings, there have been fewer opportunities to monitor the wellbeing of people with dementia who may be unable to protect their own interests. The restriction on visitors and the fear and anxiety surrounding COVID-19 may have increased the experience of loneliness, boredom and depression amongst people with dementia, and led to behaviour which other people find difficult to manage, which when combined with other factors may increase the risk of restraint being used. Howard, Burns and Schneider (2020) suggest that some of the increase in antipsychotic prescribing to people with dementia in care homes during the pandemic may well have been the result of worsened agitation and psychosis related to the confinement of care home residents to their rooms, and the cessation of group activities and visits from relatives.

The risk of harm linked to certain measures adopted during the pandemic raises questions about the proportionality of those measures in relation to people with dementia. A United Nations report on the impact of COVID-19 on older persons (2020) highlighted distressing reports of older people in care homes experiencing neglect and mistreatment,

<sup>35</sup> Reported in the United Nations Policy Brief of May 2020.

and those who are quarantined or locked down with relatives or carers also facing a higher risk of violence, abuse and neglect. The Scottish Government recently acknowledged growing evidence of direct and indirect harms resulting from the pandemic (i.e. from the virus itself but also from the protective measures adopted). They labelled these the four harms of COVID-19, namely direct, indirect, societal and economic. Nicola Sturgeon further stated:

- ▶ *“We have a duty to balance all of the different harms caused by the pandemic. We must consider the direct harm to health from the virus - which must be reduced... And we have to consider the wider harms to health and wellbeing that the virus - and the restrictions deployed to control it - are having on all of us”* (cited in Alzheimer Scotland 2020, p.9).

### Discrimination or arbitrariness

Discrimination on the basis of personal characteristics or situation (such as age, sex, gender identity, social or ethnic affiliation, disability, socio-economic status or place of residence) and the ranking of lives on the basis of value judgements or of assumptions about quality of life are unacceptable and contrary to numerous legal and ethical conventions and recommendations. The neglect of or discrimination against people with dementia, whether deliberate or due to oversight, constitutes unethical behaviour at governmental level in the form of failure to protect the rights and wellbeing of the most vulnerable members of society. The Director General of the World Health Organisation stated in relation to the COVID-19 pandemic that:

- ▶ *“All countries must strike a fine balance between protecting health, minimizing economic and social disruption, and respecting human rights”* (WHO, April 2020).

Discrimination is not always a bad thing but the term is usually used to imply negative/unfair discrimination. Any discrimination must be a proportionate means to achieve a legitimate goal, which means a goal that is not based on a discriminatory reason but rather on a reason that is genuine and real (not just made up). For example, if people with dementia were genuinely safer if confined to care homes, were guaranteed an equally high level of care in such homes (including intensive care) and would risk their own safety and wellbeing if transferred to hospital, it would perhaps not be considered wrong to impose confinement on people in that group for an appropriate period of time. The pursuit of their safety and wellbeing could be considered as a legitimate goal, although some people might argue that months if not years of absolute confinement would

be disproportionate in terms of their health and wellbeing, their right to family life (including maintaining relationships) and respect of their legal capacity (i.e. the right to decide to leave the home, to get fresh air, to receive visitors etc.). If the reason for the discrimination was based on the desire to prioritise other groups within society (e.g. people of working age, children, etc.) at the expense of the group in question, and the reason given (i.e. to protect people in care homes) was therefore not genuine, this would be unethical. Approaches and apparent solutions which result in a marginalised or stigmatized group of people bearing a disproportionate burden should lead to particular scrutiny about whether they are discriminatory.

Measures adopted during the coronavirus pandemic have deprived many people of the same rights that other people had to protect themselves and others from harm. It also amounted to discrimination based on place of residence, but also, indirectly, on age and disability because the people living in such homes were predominantly older and disabled. The singling out of whole groups of people on the basis of shared characteristics (such as age, disability, dependency or place of residence) to achieve the greatest good is still discrimination and cannot be considered a fair allocation of resources (including care) if this is arbitrary and unjustifiably targets typically devalued groups.

With regard to age discrimination in the context of scarce resources, there are reports of older people being put under due pressure to sign do-not-resuscitate orders before being given treatment (United Nations 2020). Whilst some discrimination occurs at the interpersonal level (e.g. by health and social care professionals or care home managers), responsibility also lies with governments (i.e. for structural discrimination). In its position paper on the allocation of scarce resources during the COVID-19 pandemic, Alzheimer Europe (2020)<sup>36</sup> recommended that:

- ▶ *“Governments and healthcare systems should take all necessary measures to ensure that the needed infrastructure (in addition to sufficient human resources) is in place so as to avoid the need for triage decisions.”*

The fact that many people who were (or are still being) denied adequate protection and the same quality of care as other members of society, lack the legal capacity to defend themselves and are largely stigmatized groups within society, cannot be overlooked. The frequent use of the term 'only' (e.g. only older people are seriously affected) and concerns that the virus might not 'only' affect older people or people with existing medical conditions is a constant indication of the perceived lack of value of certain groups of people,

<sup>36</sup> See <https://www.alzheimer-europe.org/Policy/Our-opinion-on/Dementia-Research-and-COVID-19>

to which many people with dementia belong. Many people with dementia, especially those living in care homes, lack the formal or informal legal capacity to ensure equal access to treatment and to be protected from harm. Resources have often been used elsewhere and many people from vulnerable groups have died. In some countries, their deaths have not always been recorded as being due to coronavirus (as there was no testing and they were not part of hospital statistics). They were cut off from direct contact with friends, families and guardians who often struggled to defend their rights without any direct access to them.

### Solidarity and reciprocity

A community ethics approach is needed which focuses on societies as a whole and in which solidarity is the norm. One reflection of this can be found in the controversial slogan “Don’t kill Granny” adopted in the north of England to encourage younger people to respect distancing measures for the good of older people (rather than putting the onus or obligation on the former to withdraw themselves completely from society). Mutual caring and respect between different members of society can be considered in the context of interdependency and solidarity, not only in relation to people confined in care homes but also cocooned in their own homes. In her speech at the recent virtual annual conference of Alzheimer Europe in 2020, Helen Rochford-Brennan (Chair of the European Working Group of People with Dementia) stated:

► *I believe that older people paid a higher price because, cocooned, we stayed at home and made sure the health service was not overwhelmed. There’s a lot of chat about protecting older people but who are you protecting? I stood in solidarity with healthcare professionals and citizens. I lit candles in the window; I put my flag in the garden. But I expect that solidarity in return and I hope that young people stand with me as I navigate through COVID.*

Reciprocity is also important with regard to people with dementia who have in the past and still do contribute towards society in different ways, but also with regard to people who provide care and support to people with dementia who are self-isolating, cocooning or whose liberty has been restricted. A society cannot be considered ethical if it neglects or discriminates against vulnerable groups. Neither can it be considered ethical if it focuses entirely on the needs of one group, even a vulnerable group, whilst neglecting those of others (e.g. healthcare professionals), especially those in high-risk categories. Mechanisms should therefore be in place to protect the lives and wellbeing of healthcare professionals and related support staff (e.g. by providing them with safe working conditions, PPE and tests for themselves and their patients/residents), whilst also recognising that some may have high personal risk factors and competing concerns about their own safety and that of their families.

### Recommendations related to restrictions of freedom during the COVID-19 pandemic

1. People with dementia should not be considered as a homogenous group in relation to the application of protective measures during the pandemic. Some people with dementia are in good health and able to follow developments and comply with safety measures.
2. Care homes should facilitate contact between people with dementia and family members, particularly when face-to-face visits are not possible (e.g. through phone calls, virtual meetings or window visits etc.).
3. Face-to-face visits should be facilitated where possible, with all due precautions taken to protect the safety of the resident, other residents, the visitors themselves and care staff. This is particularly important for people with dementia in an acute or extreme case of distress or in the last moments of life.
4. The benefits of physical distancing should be weighed against the potential and likely harm to all involved as a result of their implementation.
5. Distancing measures should be proportionate to the actual risk of residents and staff in each specific home, and this should be controlled by relevant authorities.
6. Distancing and other safety measures should be considered on a case by case basis (e.g. in relation to each care home), also bearing in mind the needs and wishes of the individual residents.
7. Just as relaxations of certain legal measures concerning involuntary placement have been implemented in some countries, it should also be possible for families and close friends to apply to the necessary authorities to care for a resident at home for a period of time.
8. Despite lack of resources, emotional stress and staff shortages, physical, mechanical and chemical restraint should not be used to manage difficult care situations. In extreme cases, if absolutely essential for the safety of the person concerned, any such use should be in accordance with legal requirements (i.e. with regard to authorisation, supervision, documentation, proportionality and revision).

9. Governments should take necessary measures to ensure that any restrictions of the freedom of people with dementia are not discriminatory, are proportionate to risk and potential benefits, and are accompanied by the following:
  - setting up a specialised team and developing a plan to address the needs of vulnerable groups during the pandemic to prevent the spread of the virus, guarantee equal access to necessary care and treatment, and to restore normal services and support post-pandemic
  - ensuring priority testing and vaccination of all health and social care staff, at all levels (e.g. including service and auxiliary staff) and irrespective of employment status (e.g. employed by the government, by private care providers or self-employed)
  - ensuring that necessary protective equipment and materials are available to service providers who come into contact with people with dementia in order to provide treatment, care and support in any setting
  - monitoring in terms of legality, necessity, proportionality, equity, fairness and respect for dignity
  - obligatory reporting of decisions made in relation to restrictions of freedom and access to emergency treatment
  - timely access to care, testing and vaccination
  - obligatory recording on death certificates of the cause of death, specifying whether the cause (or suspected cause in case the person was not tested) was COVID-19.
10. Governments should set up independent inquiries into the management of dementia care during the COVID-19 pandemic and develop guidelines to help ensure that future pandemics or similar crises are managed in a way that is ethical and legal, particularly with regard to potentially vulnerable groups in society.

## Civil and political life

People with dementia, as equally valued members of society, must be enabled, wherever possible, to exercise their civil and political rights. This covers a wide range of topics such as the right to vote, to a fair trial, to government services, to be on a jury, to a public education, to use public facilities, to stand for political office, to write a will and to marry or divorce. In this section, we look at just a few issues:

- voting
- marriage and civil partnerships
- making a will/testament.

### Voting

#### *The importance of participation in political life*

Political participation can take many forms, from involvement in political parties and civil society organisations to following the news. A report by the European Union Agency for Fundamental Rights (FRA 2014)<sup>37</sup> entitled *The Right to Political Participation for Persons with Disabilities: Human Rights Indicators*, focuses on two of the core components of political participation: the rights to vote and to be elected. These rights are particularly important for the functioning of the EU which, as set out in Article 2 of the Treaty on European Union (TEU), are “founded on the values of [...] democracy and respect for human rights”. The elections to the European Parliament every five years are one of the

main avenues for citizens’ participation in the Union, while being able to vote in municipal elections in the EU Member State in which a person lives is a key demonstration of the principle of free movement of people.

There is limited literature on the capacity (in the sense of the ability/decision making 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. However, the issue of decision-making capacity in relation to voting is problematic because it contradicts the provisions of the CRPD and also because it could be argued that voting is a political right, not a matter of the capacity to make decisions (Redley, Hughes and Holland 2010). Indeed, people do not all vote on the basis of a satisfactory understanding of political candidates’ position on various issues, may base their choices on unusual criteria and some are life-long voters of a particular political party irrespective of who represents it. None of this has much to do with decision making capacity and as the capacity to vote of people who are not disabled is not questioned or tested, any restrictions based on decision-making capacity are discriminatory and hence unethical.

The opportunity to be involved in political life, whether by standing for elected office, joining a political party, or following political news stories in the media, is at the heart

<sup>37</sup> [https://fra.europa.eu/sites/default/files/fra-2014-right-political-participation-persons-disabilities\\_en.pdf](https://fra.europa.eu/sites/default/files/fra-2014-right-political-participation-persons-disabilities_en.pdf)

of what it means to live in a democratic society. In addition, voting has been found to enhance social engagement and self-esteem (Bullenkamp and Voges 2004) and dementia does not necessarily preclude the desire or ability to vote (Karlavish et al. 2004). Failure to allow and enable people with dementia to vote fails to respect their autonomy and is discriminatory in that it does not permit people with dementia to participate in society on an equal basis with other citizens as laid down in the CRPD.

The FRA report (2014) analyses data on the situation of political participation of persons with disabilities collected from across the 28 European Union (EU) Member States by the European Union Agency for the FRA and the European Commission-funded Academic Network of European Disability Experts (ANED). The human rights indicators presented in the report show that legal and administrative barriers, inaccessible and cumbersome administrative procedures, and a lack of awareness about political rights (including difficulties accessing complaints mechanisms) can deny persons with disabilities the opportunity to participate in the political lives of their communities. The research also reveals the absence of reliable and comparable data about persons with disabilities' experiences of taking part in elections in the EU. Addressing these challenges as soon as possible is essential for increasing the legitimacy of public institutions and creating more equitable and inclusive societies in which all members can participate fully.

### *The right to vote and measures to make this possible*

Numerous CRPD articles underpin the realisation of the right to political participation. The interplay between these rights is reflected in many of the indicators in this report. In particular, the CRPD committee has established Article 12 on equal recognition before the law as central to the convention as a whole. By specifically linking Articles 12 and 29, the Committee has expressed concern that in many states, including some EU Member States, the deprivation of legal capacity triggers a limitation on the right to vote.

Accessibility is also especially important. Article 29 of the CRPD requires state parties to ensure that “voting procedures, facilities and materials are appropriate, accessible and easy to understand and use”. This is reinforced by Article 9 which requires “Buildings, roads, transportation and other indoor and outdoor facilities” used by the public to be made accessible with “minimum standards and guidelines for the accessibility of facilities and services open or provided to the public”, “public signage in Braille and in easy to read and understand forms” and “forms of live assistance and intermediaries”. Article 9 further requires state parties to

promote “access for persons with disabilities to new information and communications technologies and systems, including the Internet”.

The Convention on the Rights of Persons with Disabilities states in article 29 (Participation in political and public life) that:

*“States Parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others, and shall undertake:*

*a) To ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives, including the right and opportunity for persons with disabilities to vote and be elected, inter alia, by:*

*i. Ensuring that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use;*

*ii. Protecting the right of persons with disabilities to vote by secret ballot in elections and public referendums without intimidation, and to stand for elections, to effectively hold office and perform all public functions at all levels of government, facilitating the use of assistive and new technologies where appropriate;*

*iii. Guaranteeing the free expression of the will of persons with disabilities as electors and to this end, where necessary, at their request, allowing assistance in voting by a person of their own choice;*

*b) To promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs, including:*

*i. Participation in non-governmental organizations and associations concerned with the public and political life of the country, and in the activities and administration of political parties;*

*ii. Forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels.”*

In this framework, the Council of Europe issued “Recommendation CM/Rec (2011) 14 of the Committee of Ministers to member states on the participation of persons with disabilities in political and public life”. The short version of this

recommendation provides a straightforward summary of the above<sup>38</sup>:

► *“Taking part in political and public life: When you take part in political and public life, you can have a say in the way things are run in your community. You can make things better and fairer in your community. You can take part in political and public life in different ways. For example, you can:*

- Choose who will run your country, region or city. You can do this when you vote in elections.
- Become a candidate in elections: Tell others about your ideas on how to make things in your community better.
- Get information about the way things work in your community.
- Get together with other people to share ideas and fight for your rights.
- Start a political party or an organisation.
- Take part in public meetings and discussions.
- Say what you think about the way things are run in your community.
- Tell decision-makers what you think. Ask them to use this when they make decisions.
- Become part of the government or have public duties.”

► *“People with disabilities often find it difficult to take part in political and public life. There are different reasons, for example:*

- Laws in their country say that some people with disabilities cannot take part in elections.
- Some governments do not listen to their opinions.
- Information about politics and important things is often difficult to understand.
- Sometimes, the places where elections or public meetings take place are difficult to find and enter.
- This means that these places are not accessible.
- Sometimes, the ways things, for example voting, are done make it difficult or impossible for people with disabilities to take part.
- People with disabilities often get little help to overcome these difficulties.”

The Council of Europe recommendations seek to ensure that people with disabilities have the same rights but also the same opportunities to take part in political and public life as other people. People with disabilities need access to places, information, goods and services. Public buildings and places, including polling stations, must be easy to find and enter. Voting papers must be easy for everyone to use. Important information must be easy to read

and understandable, and people with disabilities must be able to use public transport to get to polling stations like everyone else. The way things are done, such as voting, must be easy for everyone.

Another important document related to the involvement of people with disabilities in public life is Recommendation CM/Rec (2018)4 of the Committee of Ministers to member States on the participation of citizens in local public life (adopted by the Committee of Ministers on 21 March 2018 at the 131<sup>th</sup> meeting of the Ministers’ Deputies).<sup>39</sup> Article 6 outlines the necessity to:

► *“i) create and promote possibilities for persons with disabilities to fully participate in all aspects of local public life, and take the necessary measures to allow and encourage them to do so; ii) develop and promote suitable forms of and structures for participation, removing obstacles and providing appropriate assistance as required, to involve persons with disabilities, such as advisory boards, taking into account Recommendation CM/Rec(2011)14 of the Committee of Ministers to member States on the participation of persons with disabilities in political and public life;”*

The European Economic and Social Council (2019) nevertheless noted, after having called for a lifting of restrictions on participation in the 2019 European elections, the persistence of legal restrictions due to the deprivation of legal capacity. The FRA (2020) suggests that one of the main restrictions to the right to vote is the deprivation of legal capacity which could affect some of the 264,000 people in the EU who are subject to full guardianship.

#### *Impact of restrictions of legal capacity on voting*

As highlighted in the FRA report on the right to political participation of persons with mental health problems and persons with intellectual disabilities, and subsequent updates, the right to vote is often linked in national legislation to legal capacity. This means that people who have been deprived of their legal capacity, either wholly or in part, are prohibited from voting. This possible limitation of the right to political participation does not apply to everyone with disabilities. People with psychosocial or intellectual disabilities are disproportionately affected. The CRPD states that each adult citizen has the right to vote on an equal basis with others. Reflecting this, the CRPD Committee has expressed concern over legislation that “allows for the right to vote of persons with intellectual or psycho-social disabilities to be restricted if the person concerned has been deprived of his or her legal capacity”.

<sup>38</sup> [https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg\\_no=IV-15&chapter=4&clang=\\_en](https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&clang=_en)

<sup>39</sup> <https://rm.coe.int/16807954c3>

Article 12 is relevant to the right to political participation because in many jurisdictions a person whose legal capacity has been withheld or restricted is – either automatically or through a judicial process – deprived of the right to vote and to stand for election. In some jurisdictions, people are also deprived of the right to join or form associations such as non-governmental organisations, political parties or trade unions. This calls into question the fulfilment of the principle of non-discrimination enshrined in Article 29 which states that state parties “shall guarantee persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others” (p. 36).

The CRPD Committee has commented extensively on the link between legal capacity and political participation. In its General Comment on Article 12, the Committee states that a:

- ▶ *“person’s decision-making ability cannot be used to justify any exclusion of persons with disabilities from exercising their political rights, including the right to vote, to stand for election, and to serve as a member of a jury” (p. 37).*

### *Obstacles to exercising the legal capacity to vote*

Although Article 19 of the CRPD sets out the right to live in the community, many people with disabilities, including people with dementia, live in residential/care institutions. The CRPD is clear that people with disabilities enjoy rights on an equal basis with others, regardless of where they live. Legislative procedures and provisions may be needed to ensure that people living in institutions can exercise their right to vote (e.g. to provide alternative forms of voting, set up voting booths at institutions or allow mobile ballot boxes which can be brought to institutions). Such measures should take into account the importance of guaranteeing the secrecy of the vote and ensuring that people with disabilities can vote freely for the candidate or party of their choice without undue influence from others, and can choose a person to help them express their choice or to vote, in keeping with supported decision making. In the case of people with dementia with limited decision-making capacity and difficulties with communication (including difficulty with written instructions and indicating choice on a voting slip), it would be very difficult to ensure secrecy and avoid possible manipulation or coercion by a supporting person.

It is important to consider also potential informal restrictions of legal capacity. Getting to a polling station can be difficult. Some institutions are located in remote areas and there is a lack of available or accessible transport, or residents are unable to leave the institution without assistance. There may also be some degree of gatekeeping with political candidates finding it difficult to get past care staff and reach people with dementia. Some of these barriers may be caused by lack of reasonable accommodation and

structural discrimination but also by failure to promote voting amongst people with dementia. Living in residential care homes with limited opportunities to mix with other people in the community, combined with difficulties understanding written texts and the news on television, may all contribute to a lack of awareness of the issues and political personalities of relevance to elections, even that elections are being held. Some people have voted all their lives and their political views are in part an expression of who they are and of the fulfilment of their societal responsibilities. Others may have less or no particular interest in voting but their lives continue to be impacted by decisions made by democratically elected politicians whom they did not elect or oppose. It could be argued that not making an effort to promote voting by people with dementia (without exercising any pressure to vote) is in some way harmful and fails to respect their dignity as persons and as citizens.

Perhaps worse than actively failing to promote the right of people with dementia to vote is leading people to believe that they have no such right. 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. People with dementia who are living in their own homes in the community might simply go and vote whereas those living in care homes may be subjected to assessments of their capacity. This amounts to discrimination and a possible abuse of power. It also raises the question of the competence of nurses and care staff to evaluate the capacity to vote.

Much more effort is required than simply providing information and ensuring that people with dementia know that they have the right to vote. The responsibility for reasonable accommodation is applicable to a broad range of people but clarity is needed as to who is responsible for ensuring that people with dementia really can participate in political life, through voting, on an equal basis as other members of society. If there is no law or formal procedure outlining precise requirements and responsibilities, people with dementia may continue to be excluded from political life.

### *Legislation related to the legal capacity to vote: a few examples from within Europe*

There are restrictions on the right to vote in several national laws. In Portugal, for example, the right to vote is part of the right to citizenship foreseen in article 26<sup>9</sup> of the Portuguese Constitution. It is a fundamental right. The current legal framework regulating legal capacity addresses the issue of adults who, due to their health condition, disability or behaviour, are unable to fully exercise or fulfil their rights.

Legal capacity can only be restricted by law or by a court decision. With regard to the right to vote, there are two



possibilities: 1) there is a court decision stating that the person has no capacity to vote, in which case the person does not have the right to vote; 2) there is no court decision, in which case the person can vote unless they show signs of a severe limitation of mental functioning, even when there is no court decision about their capacity, and when the person lives in a psychiatric facility or the severe limitation of mental function has been assessed by a board of two doctors.<sup>40</sup> This is governed by specific legislation on the different election procedures (i.e. to municipalities, to the Parliament or to the President of the Republic). A care home is not considered a psychiatric facility. A person living in such a home who is considered as having severe limitation of mental capacity and would like to vote could nevertheless be prevented from doing so by a person from the polling station on the basis of an evaluation and decision made by a doctor who is present at the polling station.

This means that, according to the current legal framework regulating legal capacity, in some circumstances the exercise of some legal rights may be restricted (e.g. managing property or business, making a will etc.) but the right to vote preserved. It also means that people may see their right to vote denied without any prior court decision. This is not in line with the CRPD because the right to vote is being linked to an issue of capacity and not to a political right that anyone can exercise independent of their mental status. There are also a few ethical issues linked to voting rights for people who are not in psychiatric facilities. People with dementia, living at home or in a care home, who appear to have a severe limitation of mental functioning may have their legal capacity (i.e. their legal right) to vote restricted at the request of someone running a polling station and on the decision of a doctor who has no access to the person's medical file or history and is not familiar with the person. It is easy to see how this could sometimes result in blanket decisions being made to prevent people known or suspected of having dementia from voting, based on ignorance and stereotyping. There are also issues of privacy and confidentiality linked to being singled out in public, assessed and declared as lacking the capacity to vote. This may be deeply humiliating, especially at local level where the person may be well known. The mere knowledge of this possibly happening could serve as a deterrent to some people with dementia who may rightly or wrongly assume that they would be denied the right to vote.

### *European court cases linked to the non-respect of the legal capacity to vote*

According to the FRA (2020), there were court rulings in Germany, Poland and France in 2019 concerning legal restrictions on the right to vote. A constitutional court ruling in Germany required amendments to the Federal Elections Act after ruling that the exclusion of people with guardians and people lacking criminal responsibility for a crime violated the principal of universal suffrage and the prohibition of discrimination on the grounds of disability. A Polish constitutional court ruled to restore the right of people without legal capacity to vote, and in France the right to vote of people with disabilities under guardianship was recognised.

There have also been formal complaints in Hungary against the government for failure to respect the right of people with disabilities to vote (FRA 2014). The first case<sup>41</sup> involved a man with a psychosocial disability who had automatically lost his right to vote as a result of being placed under partial guardianship. The ECHR concluded that “an indiscriminate removal of voting rights, without an individualised judicial evaluation and solely based on a mental (decision-making) disability necessitating partial guardianship, cannot be considered compatible with the legitimate grounds for restricting the right to vote” (paragraph 44). Hungary subsequently changed its constitution in 2012. Under the current Fundamental Law, judges must base their decisions on the right to vote for people deprived of legal capacity on an individual assessment. This is a positive change but still, in some cases, results in a person losing the right to vote through a court case involving an examination of decision-making capacity.

The second case<sup>42</sup> was submitted by six people with intellectual disabilities who had been placed under partial or plenary guardianship by judicial decisions and had been automatically removed from the electoral register under the provisions of the Constitution of Hungary. This led to them being excluded from the 2010 parliamentary and municipal elections irrespective of their ability or desire to vote, the nature of their disability, their individual abilities or the scope of the guardianship measure. The Committee found that Hungary had failed to comply with Articles 12 and 29 of the CRPD. The Committee also made several recommendations to the state party including compensation for moral damages, covering the legal costs incurred and several measures to prevent similar violations in the future by introducing legislative as well as procedural changes.<sup>43</sup>

<sup>40</sup> This law does not cover care homes where many people with dementia live.

<sup>41</sup> Alajos Kiss v. Hungary, No. 38832/06, Judgment of 20 May 2010.

<sup>42</sup> Zsolt Bujdosó and five others v. Hungary.

<sup>43</sup> Source: United Nations, Committee on the Rights of Persons with Disabilities (2011), Communication No. 4/2011, CRPD/C/10/D/4/2011.

People with different forms of impairment are affected in different ways. Therefore, specific measures should be developed addressing different needs in close cooperation with disabled people's organisations. People with more severe impairments, as well as people with particular types of impairment (e.g.

with intellectual disabilities), are often some of the most isolated and excluded from political and social life. Ensuring that they are also able to play a full part in the political process presents a particular challenge to EU Member States that should be addressed.

### Recommendations on voting

1. There should be clear governmental guidelines on how to maximise the potential for people with dementia, especially in residential care settings, to vote.
2. A trained and neutral supporter should be made responsible for overseeing/providing assistance to people with dementia at the polling station and by ensuring that the procedure and environment is 'dementia friendly'.
3. Special support should be provided in the case of electronic voting systems for people who are not familiar with the use of computers. This should be provided prior to and during voting.
4. Transport issues must be considered for people with dementia to ensure that they can get safely to and from polling stations.
5. A supporter of the person's choice should be allowed to enter into the voting booth with the person with dementia in order to provide assistance, if requested by the latter.
6. Absentee voting (i.e. from a distance) should be possible for people with dementia, especially those in residential care or hospitals. Safeguards are needed to ensure that it is the person with dementia who votes and that the ballot paper is posted to the correct place and before the deadline for votes.
7. 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).
8. 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.
9. Residents with dementia in care homes should have access to timely information about upcoming elections and to relevant information available to the public during the election campaigns.
10. Residents with dementia in care homes should have access to campaigning political candidates (if they so wish).
11. 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 assistance provided by that person should be provided on a non-partisan basis and people with dementia should have the right, if they prefer, to ask for assistance from any other person.
12. 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 if their legal capacity is eventually in some way restricted.
13. 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 and it is legal to do so.

### Marriage and civil partnerships

#### *Formalised/official relationships*

The right to get married (and to contract a civil partnership) is often considered as being part of a broader right to citizenship and to having a family. In many countries, this right is addressed in the country's constitution. We have included civil partnerships in the title of this section as the ethical issues linked to formalised/official relationships (either through marriage or through other legally binding

agreements) are similar but recognise that, in some countries, legislation may not apply to both.

In Portugal, article 67<sup>o</sup> of the Constitution states,

*"The family, as a fundamental element of society, has the right to the protection of society and of the State and to the fulfilment of all conditions that allow the personal fulfilment of its members".*

*This right is also addressed in article 23 of the CRPD on Respect for Home and the Family. The introduction to article 1 and subsection a) are particularly relevant:*

*"1. States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that:*

*a) The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized;"*

From a legal perspective, Glezer and Devido (2017) compare the capacity to marry with that of entering into other legally binding contracts, with the ultimate goal of assessment being "to prevent manipulation of a potentially impaired or otherwise vulnerable person through exploitative contractual arrangements and to balance respect for autonomy against beneficence and nonmaleficence".

Legislation on the right to marry varies considerably across Europe. It usually requires some level of understanding of the implications of marriage and sometimes the authorisation or confirmation of the necessary capacity by a guardian, court, administrative body, marriage official or priest. In almost all countries in the European Union, a person needs to have some level of understanding of the meaning and consequences of marriage. However, in Sweden, where up until 1989, people who were under guardianship had to obtain special permission to get married, people can now get married without having to obtain permission from their trustee or custodian. There are no explicit requirements in Swedish law that the people contracting a marriage should understand the significance of it.<sup>44</sup> In Finland, on the other hand, a person is always considered as having the legal capacity to marry but must demonstrate an understanding of the meaning and consequences of the act (Alzheimer Europe 2016).<sup>45</sup> Some countries have provisions that allow for a marriage to be annulled or declared void in case one of the two partners is found to have lacked mental capacity at the moment of marriage. This is the case in Ireland, Italy, Lithuania, Malta, Norway, Poland, Portugal, Switzerland and the UK (England). In Jersey, a marriage could be declared null and void on the grounds that the person did not have

sufficient mental capacity at the time of the marriage to understand the nature of the marriage contract and that his/her spouse was aware of the incapacity. It is not clear how these legal provisions relate to civil partnerships which may be governed by other laws.

In Portugal, the right to marry or enter into a civil partnership is considered as a personal right linked to respect for autonomy. However, under Article 1 601<sup>o</sup> b) of the Civil Code, a person who shows signs of dementia ("Demência notória"<sup>46</sup>) may be deprived of the right to marry, even if they have moments of lucidity. With the exception of Sweden, and perhaps Finland, it cannot be said that legislation reflects the provisions of article 12 of the CRPD. People with dementia who wish to marry do not automatically have the right to do so. Various laws refer to the capacity to marry, sometimes specifying the need for some understanding of the consequences of marriage. Two consequences of marriage might spring to mind, namely sexual contact and the management and sharing of capital and possessions. Marriage may also result in a person's will being revoked. As the capacity to contract a marriage may be considered as requiring a lower level of decision-making capacity than that required to make a will (Rowlatt 2018),<sup>47</sup> people with moderate to advanced dementia might find that they are not allowed to make a new will (or that if they did, it would risk being challenged later). In the UK, a statutory will might be possible but this would be based on the principle of best interests (Rowlatt 2018). Sexual contact is probably not a key consideration for people to understand because sex is not dependent on marriage and marriage does not grant either partner any automatic right in the sense that sexual acts must also be consensual between marriage partners and if not, can result in allegations of rape.

According to Glezer and Devido (2017), centuries ago, the concept of marriage and related procedures mainly reflected practical and economic goals, with little or no input from the bride or groom. Issues such as capacity and autonomy were not given much importance until some of the world's major religions (i.e. Catholic, Jewish and Islamic) started to focus on the wishes of the bride and groom, and civic legal systems followed suit. Nevertheless, much of the debate about the legal capacity to marry (ignoring for the moment that the CRPD states that people should not be deprived of their legal capacity on the basis of disability or lack of decision-making capacity) revolves around financial issues.

<sup>44</sup> Alzheimer Europe (2016), for various sources in this subsection, see: <https://www.alzheimer-europe.org/Policy/Country-comparisons/2016-Decision-making-and-legal-capacity-in-dementia/Sweden>

<sup>45</sup> For more details and references related to this subsection, please see Alzheimer Europe's 2016 Yearbook on Decision Making and Legal Capacity in Dementia - [https://www.alzheimer-europe.org/Publications/Dementia-in-Europe-Yearbooks/\(language\)/eng-GB](https://www.alzheimer-europe.org/Publications/Dementia-in-Europe-Yearbooks/(language)/eng-GB)

<sup>46</sup> This is a very old article that should have been changed according to the current legal framework on diminished capacity. It does nevertheless mean that it is only necessary to have some obvious signs which are probably symptoms of dementia. If a person has a very early diagnosis of dementia and seems to have relatively good decision-making capacity, this would not be considered "Demência notória" and the person would not be stopped from marrying.

<sup>47</sup> <https://coffinmew.co.uk/capacity-to-marry/>

Directly, this may be linked to concerns about the financial abuse of vulnerable people; indirectly, it may sometimes be linked to concerns about people's inheritance.

People with dementia may sometimes be exploited and manipulated by unscrupulous individuals who would like to benefit from sharing in their wealth and property through marriage. Supported decision making could be helpful in this respect by helping to ensure that the person is aware of the issues at stake and of possible measures that can be taken to protect possessions and capital (and perhaps reassure existing relatives about their possible future inheritance). However, if people with dementia are to have the same opportunities as other people, this includes the right to take risks and to make seemingly unwise decisions. Many people marry others for their money or status and many people enter into such arrangements willingly despite knowing or strongly suspecting that this is the case.

Restrictions of legal capacity in relation to marriages involving people with dementia may on the surface seem understandable in terms of protecting potentially vulnerable people from possible exploitation. However, they also seem somewhat inappropriate considering the very personal, emotional, physical and for some people religious or spiritual nature of marriage. The interference of adult children (who may be appointed guardians) in such matters involves a role reversal with implications for social roles and self-esteem. The need for authorisation to marry also involves a forced symbolic regression to pre-adult status which is demeaning.

Glezer and Devido (2017) emphasise the importance of the person expressing a consistent choice, understanding the risks, benefits and possible alternatives to the decision, not having a condition that is hindering rational thought and knows with whom they are entering into marriage. They nevertheless point out that marriage is a form of contract but is very different from other contracts such as land leases and that there are relational as well as spiritual and religious implications and stakes. The direct application of principles of decision-making for consent to medical treatment such as those proposed by Appelbaum (2007) may also seem somewhat inappropriate. Therefore, although healthcare experts might be involved in assessing decision-making capacity, Glezer and Devido advise healthcare teams to seek expert consultation from relevant spiritual and religious communities in order to gain a better understanding of factors that may be influencing some people's decisions about marriage.

### *Informal relationships*

It sometimes happens that a person with dementia moves into a care home, forgets at some point that they are married or have a partner and starts a relationship with another person. In some cases, this might reflect the need for physical contact or affection or be a case of mistaken identity

(e.g. believing that another resident is their current or former partner) (Alzheimer's Society 2020). Relatives and care staff may sometimes have concerns about the welfare or safety of a person with dementia who has started a new relationship (irrespective of their marital status), fearing perhaps that they are being taken advantage of or abused, or that they may be at risk of contracting a sexually transmitted disease. There may also be concerns linked to financial issues (e.g. if the married couple has joint bank accounts and if the one in the care home starts spending large sums of money in connection with the newly formed couple). Values and beliefs, reflected in attitudes towards money, relationships, morality and sexuality, may change in the course of a person's life and in response to changed life experiences. Partners, offspring and friends may sometimes have difficulty accepting this.

Care staff may find it difficult to manage new relationships between residents who have dementia. Spouses or partners may also be affected in different ways. For some, it may be a kind of release and an opportunity to start a new life themselves, whereas for others, it may be deeply disturbing or it may involve practical and emotional challenges. It is unfortunately not rare for care home staff, spouses/partners or legal representatives to separate newly formed couples and prevent them from having a relationship. Whilst new relationships involving people with dementia can be awkward and challenging for other people sometimes, if the person with dementia is able to maintain a meaningful relationship, it is likely that they are also able to understand the situation, with appropriate and sensitive support, and to work towards a resolution of various issues and concerns.

### *Divorce*

The issue of divorce and legal capacity is also important but has received less attention. Apart from the emotional impact, particularly if one of the parties does not wish to divorce (or end a civil partnership), divorce can be equally devastating financially. According to Article 1781<sup>o</sup> of the Portuguese Civil Code, changes in mental faculties, lasting for more than a year, which compromises (i.e. has a devastating effect on) the couple living together, may be considered legitimate grounds for the other partner to request a divorce. If the person who wants to divorce has been declared by a court as needing support to fully exercise their legal rights, they can do this alone or through the "acompanhante" (supporter), in which case the supporter would need to obtain authorisation from the court to request divorce proceedings. It therefore seems that restrictions of legal capacity can have more far reaching consequences for people with dementia in relation to marriage than to divorce. In Finland, on the other hand, if it is clear that a relationship is over and that the spouse is merely using the marriage in order to financially abuse the spouse with incapacity, the guardian of the latter is entitled to file for a divorce on behalf of that person (Alzheimer Europe 2016).

Overall, the restriction of legal capacity, especially if decision-making power has been given to the spouse/partner, could interfere with the ability to apply for a divorce and not to lose out on the settlement (i.e. financially but also

regarding place of residence and access to the couple's children). Support would definitely be needed in such cases not only of a lawyer but also of a neutral supporter (like a personal ombudsperson).

### Recommendations on marriage, civil partnerships and informal relationships

1. People with dementia should not be declared as lacking the legal capacity to marry, divorce or start/end a partnership/relationship solely on the grounds that they have a diagnosis of dementia or are subject to a guardianship measure.
2. People should not intervene or interfere with decisions related to formal or informal relationships involving people with the dementia if the latter have the relevant decision-making capacity, are not being exploited, abused or taken advantage of, appear to be comfortable in starting, maintaining or ending a relationship, and are acting in a way that is in keeping with their known current values.
3. Guardians should not have the power to prevent people with dementia from marrying, divorcing or starting/ending a partnership/relationship. They should, however, depending on the nature and extent of the powers granted to them, highlight any concerns they may have to the guardianship authorities about possible financial exploitation or abuse.
4. Genuine concerns about the wellbeing and safety of a person with dementia with regard to relationships should be communicated to the relevant people or authorities (e.g. the care home manager, relevant health or social care professionals or the police).
5. Governments should set up procedures to address the concerns of any person with a legitimate interest in the wellbeing of the person with dementia. The aim of such procedures should be to protect the person's financial interests (e.g. by means of a prenuptial (before marriage) or postnuptial (after marriage) agreement spelling out how the couple will divide their assets in the event their marriage dissolves), not to prevent the person with dementia from marrying, divorcing or starting/ending a civil partnership.
6. It should be possible for people with a legitimate interest to apply to a court for a provisional block on the transfer of property rights or finances resulting from the marriage, divorce or civil partnership until a satisfactory solution has been found and for this request to be challenged by the person concerned.
7. All discussions surrounding issues related to the decision of a person with dementia to marry, divorce or start/end a civil partnership, where there are doubts about their decision-making capacity, should be made in the context of an appropriate shared and/or supported decision making approach. This could, depending on the wishes of the person with dementia, involve supporters, ombudspersons, legal advisors, doctors and religious or spiritual leaders (if relevant).

### Making a will/testament

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. As with advance directives, it is one aspect of life where the principle of every person having legal capacity, regardless of disability and of decision-making capacity, is not easily applied and testamentary capacity can be challenged retrospectively (see subsection on challenging testamentary capacity retrospectively). Jacoby and Steer (2007) point out that dementia and personal wealth are both increasing and suggest that dementia and will making are awkward bed-fellows.

#### *Criteria for testamentary capacity (the legal capacity to write a will)*

The capacity to make a will is one form of capacity amongst others. Lack of decision-making capacity in other areas of life cannot be considered as proof of the incapacity to make a will. At the same time, a person might write a will alone with no witnesses and the document would be considered legally valid in some countries. Nevertheless, it is possible that the will of a person who had dementia when it was written might be later challenged. A person is generally considered to have testamentary capacity if they fulfil certain criteria, namely that they:

- understand the nature and effect of a will (i.e. that it involves making provisions to dispose of their money, possessions and assets),

- are of sound disposing mind (i.e. can recognise the extent and character of the property, not necessarily down to the last Euro, and dispose of it with understanding and reason),
- can understand and recall the claims of potential heirs (i.e. the expectations of people whom they might be including or excluding from the will),
- do not have a disorder of the mind, such as delusions or hallucinations, which would influence their decisions (i.e. that might result in them making bequests in the will that would otherwise not have been included),
- are not subject to undue influence or pressure from others,
- understand that making a new will revokes any previous wills.

The condition that testators should not have a disorder of the mind which could influence their decisions raises a few issues. First, it is reminiscent of the status approach which equates a medical condition or impairment with decision-making capacity and considers this sufficient grounds to revoke legal capacity, regardless of a person's actual capacities. Second, it does not account for lucid intervals and third, with regard to delusions, it does not differentiate 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). According to Davis (2005), neither necessarily corresponds to a lack of testamentary capacity. Testators must only be free of interfering delusions and this is not dependent on the absence or presence of a medical diagnosis. Shared and supported decision making, not limited to the involvement of people who might be considered as future beneficiaries, could be helpful in ensuring clarity on these issues and may be helpful in case of future challenges of a will.

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 situations 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.

### *Testing/confirming testamentary capacity*

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, however, is that testators may have adversarial relationships with other members of the family or there may be two or more parties contending for an inheritance (Bursztajn and Brodsky, undated). Also, testamentary capacity, like other capacities, is situation-specific which means that the decision-making capacity needed for simple, uncomplicated wills is much lower than that for more complex legacies (e.g. involving larger sums and complex family dynamics) (Shulman et al. 2007).

Doctors, notaries and members of the general public are sometimes asked to certify or bear witness to a person's perceived testamentary capacity. In Portugal, for example, a notary has to be sure that a person has the capacity to make a will. According to article 173<sup>o</sup>, n<sup>o</sup> 1 c) of the Code of Notary, in case of doubt about the mental capacity of the person, notaries must refuse to perform the notarial act relevant to the will and seek medical certification of the person's capacity (article 67, n<sup>o</sup> 4 of the same Code). It should be noted that in Portugal the will is written by the notary, not by the testator, who just signs together with two witnesses who cannot be relatives of the testator or of each other. The Portuguese Law is very strict about how a person's will is expressed. It must be clear and gestures or monosyllabic responses to questions asked by notaries are not permitted. The will is a personal act and it is not possible to be made by a representative which would presumably rule out 100% support described in the CRPD. A court<sup>48</sup> may also declare that someone lacks the capacity to make a will (e.g. when a person is subject to a certain guardianship measure).

When it is difficult to determine such capacity, neuropsychological instruments are used to support the court decision. However, some instruments that are used are not sufficiently developed, professionals are not trained to use them

<sup>48</sup> medidas de acompanhamento de maior.

and they have not been adapted to the specific populations on which they are used. Creating, adapting and training people in their use is very important in order to respect the autonomy of people with limited decision-making capacity.

In Portugal, a specific instrument has been developed to determine the capacity to make a will, based on a functional approach to legal capacity, but also taking into account cognition, emotional aspects, personality and quality of life in order to provide comprehensive information about each person's functioning and the context, the interaction between the individual and family members and other people, congruence or incongruence of functioning within everyday life (Sousa, Vilar, Firmino and Simões 2015). Other issues such as consistency between current and past values and preferences are also considered important, accepting that these may sometimes change as a result of lived experience.

Doctors, including general practitioners, are increasingly being asked by courts, notaries and testators to certify people's capacity to make a will. Some doctors feel ill-equipped and lack the necessary expertise to fulfil this task. The capacity to dispose of one's possessions should not be confused with the capacity to consent to treatment. A certification of capacity by a doctor does not guarantee the validity of a will but merely provides high quality evidence in the case of a future legal challenge (Jacoby and Steer 2007). This is a considerable responsibility and if not done properly, does little to promote respect for a person's autonomy. There is also an issue of trust. People with dementia place their trust in doctors to make an accurate assessment of their capacity and in the legal system to ensure that their wishes are respected after their death, which is something that they will never know. Jacoby and Steer (2007) (an old age psychiatrist and a solicitor) have provided guidelines on how to assess capacity which, whilst based on the UK legal system, contain some useful advice that could be helpful to doctors in other countries.<sup>49</sup>

### *Challenging testamentary capacity retrospectively*

In most countries, a will can be challenged retrospectively based on an alleged inability to make a will. Such inability, if proven, would mean that the person was not considered as having had the legal capacity to make a will and the will could be considered null and void. It has been suggested that the growing number of people with dementia creates a fertile ground for challenges to wills (Shulman et al. 2007). Medical doctors are regularly asked to assess retrospectively patients' testamentary capacity. They often rely on limited evidence from medical files and prior scores on the Mini-Mental State Examination (MMSE – Folstein, Folstein and McHugh 1975) or other measures of cognitive function.

The MMSE is not a measure of testamentary capacity but it continues to play an important role in retrospective assessments of testamentary capacity. It is important to have instruments that specifically measure testamentary capacity and preferably can also be used to some extent retrospectively.

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 wrote the will, based on memories of the person in the time leading up to their death when they had few remaining capacities, and not of the time when the will was written, when that person may have had the necessary capacity. There may also be a discrepancy between the assessment of capacity when the will was made and the retrospective assessment of capacity in terms of information provided, people involved and access to supporting documents (Redmond 1987). The initial assessment is often made by people who have little if any knowledge of the testator. There is sometimes a basic presumption that a person has testamentary capacity, unless there are clear signs that this might not be the case. When a will is challenged, medical records are consulted and relatives and expert witnesses are interviewed who knew the person well. 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. In Portugal and most other countries, a will can be revoked if it can be proven that a person permanently or temporarily lacked testamentary capacity when the will was made. However, Mäki-Petäjä-Leinonen (2010) points out that in Finland retrospective challenges to wills by relatives are rarely successful as it is difficult to obtain evidence of lack of testamentary capacity.

Insofar as provisions exist for people to exercise their autonomy by stating their wishes in advance, some of the measures and discussions surrounding the need to protect vulnerable people from abuse could be considered disproportionate and paternalistic. As wills come into force on a person's death, harm to that person must be related to the person's retrospective wellbeing, to the spirit of their expressed autonomy and to the person's interests which are

<sup>49</sup> See: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1925203/>

believed to extend beyond death. This might be particularly relevant for people whose emphasis in life was on the family unit or on some other significant relational ties or even values (e.g. based on philanthropy or altruism). Respecting wishes would therefore be a sign of respecting the will and preferences of a person and that person's life values and

goals. Challenges to a person's will are much more likely to focus on the interests of people who felt they should have inherited something and that someone else should not. This is regulated in some countries where the children of a diseased person automatically have a legal right to a percentage of their parents' patrimony.

### Recommendations on making a will/testament

1. In keeping with supported decision making and bearing in mind the risk of abuse, every person should have access to an independent supporter to make a will and to include members of their entourage in this process if they wish.
2. Such support should aim to promote decision-making capacity and enable people with dementia to retain legal capacity to make a will for as long as possible.
3. A diagnosis of dementia should not be considered the sole justification for loss of testamentary capacity.
4. The stage of dementia and/or evidence of delusions should only be taken into consideration if they are considered relevant to and likely to have an adverse effect on decisions made by the testator in their will.
5. Healthcare 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.
6. Governments should ensure that healthcare professionals and notaries have access to support and information on how to assess testamentary capacity, especially in the case of people who already have some degree of cognitive impairment.
7. 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).
8. 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) and/or visually recording their will (e.g. on videotape or digitally).
9. Appropriate and reliable assessment tools should be developed for doctors, notaries and lay witnesses.



## 5. Conclusion

It is important to be attentive to the needs and wishes of people with dementia in order to ensure that they are enabled to participate in society on an equal basis with other citizens in all areas of life. This includes recognising everyone's dignity and personhood, along with their hopes, fears and preferences. Legal capacity is not only about the right to make decisions about one's own life but about having the opportunity to exercise that right (e.g. not only having the right to vote but also to receive information about the different candidates and to be able to get to the polling station on election day or to post one's vote). It covers key decisions in life such as where to live, managing personal finances and informed consent to medical treatment but also seemingly minor issues and freedoms such as going out for a walk, making oneself a cup of tea or coffee, buying someone a present or going on holiday. Sometimes little decisions can have a huge impact on people's well-being and quality of life. They are also ways of expressing who we are and hence fundamental to our sense of self and identity.

In some situations, people with dementia may be unable to make a particular decision, even with all possible support, and there must be practices and procedures in place to ensure that substitute decision-making is possible. Such

practices and procedures must be carefully designed and closely monitored to ensure that they are both legal and ethical. It is essential to work towards an inclusive society in which people with dementia are supported as much as possible to exercise their legal capacity, based on initial assumptions that this is possible with appropriate support and reasonable accommodations and better support for people involved in combined supported decision making (see page 22).

Stereotypes and paternalistic attitudes often lead to practices which interfere with people's formal and informal legal capacity. Members of society need to work together to remove obstacles, whether they be legal or based on mentalities, traditions or taken-for-granted limiting assumptions (e.g. that's just the way it is done, it has always been like that etc.). This is a task for everyone not just for lawmakers, policy makers, health and social care professionals and notaries. Not everyone has the power to bring about changes directly, but everyone has the power to raise issues and challenge practices, procedures and attitudes. We hope that this report has been successful in raising awareness about the many issues related to legal capacity and decision making in the context of dementia.

## 6. Glossary

### Antipsychotic medication

Antipsychotics are drugs that are generally used to treat psychosis, which is the medical term used to describe symptoms of psychosis (seeing and hearing things that are not there).

### Autonomy

The ability to make an informed and uncoerced choice in accordance with one's own values and interests, albeit with necessary support.

### Beneficence

All forms of action intended to benefit or promote the good of other people.

### COVID-19 pandemic (or coronavirus)

COVID-19 is the disease caused by a new coronavirus called SARS-CoV-2. A pandemic is a worldwide epidemic or one which covers a very wide area. It crosses international boundaries and usually affects large numbers of people.

### Covert medication

Covert medication involves the intentional administration of medication in a disguised form, usually in food and drink, resulting in someone unknowingly taking medication (i.e. without their consent).

### CRPD

Abbreviation for the United Nations Convention on the Rights of Persons with Disabilities, which came into force in 2006.

### Decision-making capacity

The ability to make a decision (with appropriate support if needed).

### Dementia

A set of symptoms, including loss of memory, mood changes, and problems with communication and reasoning. There are many causes of dementia, the most common being Alzheimer's disease and vascular dementia. Dementia is a progressive condition. This means that symptoms become more severe over time and that people with dementia typically need support and eventually care as their dementia advances.

### Disability

According to the CRPD, disability "results 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" (CRPD 2006, Preamble e).

### Discrimination

Usually, discrimination refers to the situation in which people are treated differently on the basis of certain characteristics, whereby such differential treatment is considered as being in some way detrimental to them or unfair.

### Equality

Equality involves treating everybody in the same way without taking into account differences between people, which may be inherent, linked to circumstances or structurally determined.

### Equity

Equity is not about simply providing everyone with the same opportunities but about fairness and equality in outcomes. Issues related to inequity need to be addressed when striving for equal opportunities and outcomes. This often calls for some people to be treated differently.

### Guardianship

Guardianship, in the context of this report, is the term used to refer to situations where a legal representative (e.g. a guardian, tutor or curator) takes legally binding decisions for a person placed under a protective measure.

### Impairments

Any loss or limitation, albeit physical, physiological, cognitive, sensory, psychological or mental in nature, that may contribute (in combination with other factors) to disability.

### Legal capacity

This term is used to refer to the right to make decisions for oneself, within the constraints of the law, which must then be recognised as being legal and hence respected.

### Non-maleficence

Not doing what might be harmful to or hurt somebody.

### Power of attorney

A power of attorney is a legal document that allows someone to act on someone else's behalf (e.g. when the latter loses the decision-making capacity or simply wishes someone else to make decisions or transactions on their behalf).

### Psychotropic medication

A psychotropic drug is one that affects behaviour, mood, thoughts or perception. It's an umbrella term for a lot of different drugs. Psychotropic drugs often given on prescription include, for example, anti-anxiety agents, antidepressants, antipsychotics (see above), mood stabilisers and stimulants. Some of these drugs can have very serious side effects.

### Reasonable accommodation

Reasonable accommodation is a term used in the CRPD (see above) to describe reasonable adjustments or adaptations that should be made to ensure that people have the same opportunities (e.g. to use services, access buildings and play a role in society).

### Restraint

In this report, the term 'restraint' is used to refer to any method, device, substance, act 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.

### Substitute decision making

A situation in which a person (e.g. with dementia) is unable to make a decision and another person, with the necessary and relevant authority to do so, makes a decision on that person's behalf.

### Supported decision making

Supported decision making involves providing the necessary support for someone to make a decision whereby that person retains their legal capacity, even though they would not have been considered capable of deciding in the absence of that support.

### Stigmatization

This is a process and a complex social phenomenon involving the identification and labelling of socially salient attributes, negative stereotyping, cognitive separation, devaluation and negative emotional responses, within the context of unequal power relations.

### Testamentary capacity

This is a legal term used to describe a person's legal and mental ability to make or alter a valid will.

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# Appendix 1 – Details of the members of the expert working group



Dianne Gove, PhD, is Director for Projects at Alzheimer Europe. She was Chair of the working group addressing ethical issues related to legal capacity. Her background is in psychology, education and psychotherapy. In 2013, she was awarded a PhD by the University of Bradford for her research into general practitioners' perceptions of dementia and how these relate to stigma. Her current work focuses mainly on promoting Public Involvement in research projects and on addressing ethical issues in various research projects in which Alzheimer Europe is involved.



Carmel Geoghegan became the primary carer for her Mum in January 2011 and supported her to the end of life in January 2014. Since this life changing experience, Carmel has been campaigning to keep the spotlight on dementia and end-of-life care as a national health priority in rural Ireland. Carmel has successfully organised two conferences on 'Living with dementia in rural Ireland', which brought together experts from all sections to work together to help feed into policy and practice at national level. Carmel was also a member of Alzheimer Europe's ethics working group on dementia and disability.



Jean Georges has been the Executive Director of Alzheimer Europe since 1996. Prior to this, he worked as a journalist and as a parliamentary assistant to members of the Luxembourg and European Parliament. He was responsible for setting up the European Dementia Ethics Network in 2008 and has since contributed towards several ethics projects in that context (e.g. on the use of assistive technology for and by people with dementia, ethical dilemmas faced by people with dementia and carers, dementia as a disability, inclusive research and intercultural care and support).



Dr Alistair Niemeijer (PhD) is Assistant Professor in Care Ethics at the University of Humanistic Studies, Utrecht in the Netherlands. His line of research focuses on precarious practices of care and

well-being of and for the (chronically) vulnerable by exploring different methodologies in order to answer the question how to best understand and communicate lived experiences of those whose voices have formerly been missing.



Jim Pearson is Alzheimer Scotland's Director of Policy & Research and is responsible for Alzheimer Scotland's public policy engagement. He has a background in welfare rights and a particular interest in promoting as well as protecting the rights of people living with dementia. He played a significant role in developing Scotland's Charter of Rights for people with dementia and their carers, which puts human and other legal rights at the heart of each commitment of Scotland's first and second dementia strategies. Jim has an MBA from Glasgow Caledonian University and joined the Board of Alzheimer Europe in 2014.



Dr Catherine Quinn is a lecturer in dementia studies at the Centre for Applied Dementia Studies at the University of Bradford (United Kingdom) where she teaches about post-diagnostic support. Catherine's research focuses on how we can better support people living with dementia and their carers, both through gaining a better understanding of what enables people to 'live well' and through the development of psychosocial interventions. Catherine also has an interest in relationship dynamics and positive experiences in providing care.



Sebastian Ritzi studied Care and Philosophy for the teaching qualification in vocational schools and the upper secondary level of education at Heidelberg University. He is a nursing specialist in geriatric-psychiatric nursing and has several years' professional nursing experience in Germany and Switzerland. He is a member at the graduate program "People with Dementia in Acute Care Hospitals" funded by the Robert Bosch Foundation at the Network Aging Research (NAR) as well as a research associate, teacher, and course coordinator at the Institute of Gerontology at Heidelberg University. In the context of his doctoral thesis and research,

he mainly concentrates on the ethical issues of the use of (physical) restraints on people with dementia.



Helen Rochford-Brennan is from Tubbercurry in County Sligo, Ireland. Helen spent many years working in the tourism and disability sectors and has also devoted tireless years to community activism, working at board level in several organisations. In July 2012, Helen was diagnosed with early onset Alzheimer's disease. She has been Chair of the Irish Dementia Working Group and is a member of the EWG-PWD for which she was Vice Chair and then Chair from October 2014 until 2020. She uses her time to raise awareness of dementia and raise the profile of human rights for people with dementia. In 2018, Helen was conferred with an honorary Doctor of Laws degree at NUI Galway.



Matthé Scholten has a PhD in Philosophy from the University of Amsterdam and works as a researcher at the Institute for Medical Ethics and History of Medicine of the Ruhr University Bochum

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Maria Do Rosário Zincke Dos Reis was born in Lisbon and has a Law Degree from the Lisbon Law Faculty (1985). She has worked since 1987 as a lawyer especially dedicated to the rights of people with diminished capacity. She is a trainer on the legal rights of people with diminished capacity, a Board member of Alzheimer Portugal and of Alzheimer Europe. She has also been a member of CEIC - Ethical Committee for Scientific Research (since 2017) and she has been a member of the Strategic Committee at the Lisbon Faculty of Pharmacy since 2019.

## Appendix 2 – Personal ombudsperson in Skåne (Sweden)

Information by Maths Jespersen kindly reproduced from <http://po-skane.org/in-foreign-languages/> (2015).

A service which offers supported self-decision for persons with severe psychosocial disabilities

I will tell you a little about our service PO-Skåne, which is a concrete example of supported decision-making for persons with mental health problems of the most difficult sort (living entirely in a symbolic world of their own, living barricaded in their apartment or living homeless in the streets).

As the time is short, I will make this presentation in brief paragraphs.

- It's hard to translate our Swedish word 'personligt ombud' into English, but I translate it here as 'personal ombudsperson' but will henceforth use the abbreviation PO
- A PO is a professional, highly skilled person, who works to 100 % on the commission of his client only. The PO is in no alliance with psychiatry or the social services or any other authority, and not with the client's relatives or any other person in his surroundings
- The PO does only what his client wants him to do. As it can take a long time – sometimes several months – before the client knows and dares to tell what kind of help he wants, the PO has to wait, even though a lot of things are chaotic and in a mess
- This also means that the PO has to develop a long-time engagement for his clients, usually for several years. This is a necessary condition for developing a trustful relation and for coming into more essential matters.

The social model of disability says that the problem is not within the individual, but in the society which does not meet this person in such a way that he can function. This applies also to problems with legal capacity. It's not a problem inside the individual – which should be met by forced intervention or guardianship – but society must relate in another way to this person, so that his disabilities regarding legal capacity diminishes.

Supported decision-making is an example of this. If some persons have heard to express and communicate their wishes, the solution is not to put in a guardian, but to develop a relation and ways, which make it possible for this person to express and communicate what he wants.

In our service with personal ombudspersons the most important thing has been to develop ways to work which are adjusted to this special group of persons with mental health problems of the most difficult kind. In other projects it is usually the clients who have to adjust themselves to a bureaucratic system, but we work in the opposite way. The PO's have to be very flexible and creative and unconventional in finding ways to work with this group.

I will here give you some examples of conditions which we think are necessary if you really want to reach these persons and practise supported decision-making with them:

- The PO doesn't work Monday-Friday at office hours only. The week has 7 days and each day 24 hours – and the PO must be prepared to work at all these various hours, because their clients' problems are not concentrated to office hours and some clients are more easy to contact in evenings and weekends. The PO has to work 40 hours a week but makes up a flexible working-scheme every week according to the wishes of their clients.
- The PO hasn't got any office, because "office is power". The PO works from his own home with the help of telephone and internet – and he meets his clients in their home or at neutral places out in town.
- The PO works primarily according to a relation-model. As many clients are very suspicious or hostile, or hard to reach because of other reasons, the PO has to go out and find them where they are – and then he has to try to reach them through several steps: 1. Making contact, 2. Developing a communication, 3. Establishing a relation, 4. Starting a dialogue, 5. Getting commissions. Each of these steps can take a long time to realize. Just to get contact can sometimes take several months. It could mean going out and start talking with a homeless psychotic person in a park or talking through the mail drop with someone who lives very barricaded. Not until a relation is established and a dialogue has started can the PO start getting commissions from his client.
- There should be no bureaucratic procedure to get a PO. If a form had to be signed or an admission note was necessary, many psychiatric patients would back out and not get a PO – and it would probably be the persons who need a PO most. To get a PO from PO-Skåne doesn't involve any formal procedure. After a relation is established the PO just asks "Do you want me to be your PO?". If the answer is "Yes" the whole thing is settled.
- The PO should be able to support the client in all kinds of matters. The priorities of the client are usually not

the same as the priorities of the authorities or the relatives. According to 10 years of experience the clients first priorities are usually not housing or occupation, but existential matters (why should I live? why has my life become a life of a mental patient? have I any hope for a change?), sexuality and problems with relatives. A PO must be able to spend a lot of time talking with their client also about these kinds of issues – and not just fix things.

- A PO should be well skilled to be able to argue effectively for the client's rights in front of various authorities or in court. All PO's of PO-Skåne have some kind of academic degree from the university or some similar education. Most of them are trained social workers, but some are lawyers and some have other specialised training.
- There should be PO's of various ethnic backgrounds to secure that psychiatric patients of ethnic minorities also

get PO's. It's hard to develop a personal relation if the PO and the client have language-problems. PO-Skåne has for example one PO who was born in Somalia (and raised in the United Arab Emirates) and one from Iran and one from Romania.

- The client has the right to be anonymous for the authorities. If he doesn't want his PO to tell anybody that he has a PO this must be respected. PO-Skåne gets money from the community for the service, but there is a paragraph in the contract that says that the PO could deny to tell the name of their clients to the community.
- The PO doesn't keep any records. All papers belong to the client. When their relation is terminated, the PO has either to give all papers to the client or burn them together with the client. No paper and no notes will remain with the PO.

# Appendix 3 – Criteria and questions to ask when considering the possible use of restraint in the acute hospital care setting

This is an extract from a text by: Narchi J & Ritzl S (2019). Freiheitseinschränkende Maßnahmen bei Menschen mit kognitiven Beeinträchtigungen im Akutkrankenhaus. *Geriatrie up2date*, 1(03), 267–280. <https://doi.org/10.1055/a-1008-4347>. Translated and reproduced with kind permission from Georg Thieme Verlag KG.

## 1. Criterion of proportionality

- Is the restraining measure suitable, necessary and appropriate for the objectives for which it is to be applied?
- Is the restraining measure indicated from a nursing and medical point of view or are personal, organisational and economic interests the primary concern?
- Are there milder forms of restraining measures that promise the same or greater benefit?
- Are there alternatives to the restraining measure that promise the same or greater benefit?
- Is the restraining measure truly effective in preventing the harm that needs to be averted?
- Is the intensity of the restraining measure appropriate to the situation concerned?
- Is the duration of the restraining measure appropriate to the situation concerned?

## 2. Criterion of non-maleficence

- Does the restraining measure pose a risk of causing other physical or psychological harm?
- Does the restraining measure pose the risk of a danger to life (e.g. through strangulation)?
- Does the restraining measure increase the risk of falling?
- Does the restraining measure involve any adverse effects on the healthcare situation (e.g. forced incontinence)?
- Does the restraining measure cause a loss of mobility and independence?
- Does the restraining measure directly or indirectly imply a form of humiliation?
- Does the restraining measure evoke mistrust, fear and imbalance of power?
- Does the restraining measure increase the occurrence of behaviour that is perceived as challenging (e.g. motor restlessness and shouting)?

- In the case of chemical restraint: Does the drug have harmful or irreversible side effects on body and soul?

## 3. Criterion of last resort

- Have all other possible alternatives to the restraining measure been tried and found to be ineffective, leaving the restraining measure as the last resort?
- Have all mechanical alternatives to the restraining measure already been explored?
- Have all non-mechanical alternatives to the restraining measure already been explored?
- Does the nursing documentation indicate the ineffectiveness of alternative means to the restraining measure (e.g. clear nursing reports, case discussions, protocols of fall events)?
- Is the restraining measure the last option in the decision-making process or rather the first course of action?

## 4. Criterion of self-determination

- Is the restraining measure compatible with the patient's actual or presumed will?
- Can the patient's actual will be ascertained?
- Can the patient's presumed will be ascertained?
- Has the patient's presumed will been investigated with the participation of the person concerned as well as relatives, caregivers, physicians and nursing staff?
- What is or was the patient's presumed attitude towards the use of restraint and what reasons is this position based on?
- How would the patient feel about the use of restraint if he/she knew about the associated health risks and about suitable milder alternatives?
- Does the patient's biography allow us to draw conclusions about his or her attitude towards restraint?
- Does the patient verbally or non-verbally communicate approval or disapproval (e.g. repeated shaking of the bed rail or attempts to remove the measure)?

## Conclusion

Freedom restraining measures may at first glance still seem indispensable when caring for people with cognitive impairments in hospital. For many, it is hard to imagine professional care without them. Fortunately, however, research is increasingly showing that this need not be the case: It may well be worthwhile to “do without” these measures i.e. to consider alternative interventions which can better meet the needs

of people with dementia and cognitive impairments in the acute care hospital setting in a more holistic way.

For a reflected as well as professionally, legally and ethically informed approach to freedom restraining measures, it is important to be familiar with the basic categories, definitions and empirical data on the subject. We hope that this article helps contribute to this.

