

# Dementia in Europe Yearbook 2016

Decision making  
and legal capacity  
in dementia



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## Table of contents

<b>1.</b>	<b>Foreword</b>	<b>5</b>
<b>2.</b>	<b>Introduction</b>	<b>7</b>
2.1	Background to the report	7
2.2	Relevance of the topic and layout of the report	8
2.3	Personal accounts	9
<b>3.</b>	<b>The concept of legal capacity</b>	<b>11</b>
3.1	Key international conventions and recommendations	11
3.2	Mental capacity and legal capacity	12
3.3	Assessment of mental capacity	12
3.4	Capacity is not a unitary concept	13
3.5	Specific versus general capacity	13
<b>4.</b>	<b>Legal capacity in European legislation</b>	<b>15</b>
4.1	Contractual capacity	15
4.2	Testamentary capacity	16
4.3	Criminal responsibility	17
4.4	Civil responsibility	17
4.5	Marriage	18
4.6	The right to vote	19
4.7	Personal accounts	20
<b>5.</b>	<b>Consent to treatment and research</b>	<b>23</b>
5.1	Informed consent and dementia	23
5.1.1	An overview of the concept of informed consent	23
5.1.2	Consent as a fundamental human right	23
5.1.3	Consent in the case of dementia	23
5.2	Consent to treatment	24
5.2.1	Relevant legislative frameworks and codes of medical ethics across Europe	24

5.2.2	Who can give consent if the individual is unable to consent? Substitute decision making and self-determination .....	27
5.2.3	Advance directives .....	29
5.3	Consent to research .....	30
5.4	Personal account .....	34
<b>6.</b>	<b>Systems of substitute decision making .....</b>	<b>37</b>
6.1	Court appointed decision-makers (guardianship) .....	37
6.1.1	The legal framework .....	37
6.1.2	Understandings of capacity .....	39
6.1.3	Degrees of deprivation in the different national legal frameworks .....	39
6.1.4	Principles of proportionality and subsidiarity .....	42
6.1.5	Who can ask for a guardian to be appointed? .....	43
6.1.6	The involvement of the person under guardianship and the right to be heard .....	45
6.1.7	Who appoints a guardian? .....	46
6.1.8	Who can be appointed as guardian? .....	46
6.1.9	Powers of a guardian: scope and limits of the guardian's authority .....	47
6.1.10	Involvement of the person in decision making .....	47
6.1.11	Safeguards and protection of people under guardianship from misuse of power .....	50
6.2	Anticipated measures set up by the affected individual: power of attorney .....	52
6.2.1	Power of Attorney .....	52
6.3	Personal account .....	54
<b>7.</b>	<b>Conclusions .....</b>	<b>57</b>
	<b>Acknowledgements .....</b>	<b>60</b>
	<b>References .....</b>	<b>61</b>
	<b>Appendix 1: Legislation on Advance Directives (AD) across Europe .....</b>	<b>62</b>
	<b>Appendix 2: Powers and obligations of guardians .....</b>	<b>66</b>



# 1. Foreword



It gives me great pleasure to present this comparative report on decision-making and legal capacity issues in dementia.

This is not a new topic for Alzheimer Europe. We started looking at these issues almost two decades ago. Already in 1997,

we received EU funding for the Lawnet project to collect, translate and compare legislation relating to the rights of people with dementia from the then 15 Member States of the European Union. This resulted in the publication of comprehensive national reports describing legislation in these countries and in a comparative report. We then identified countries with legislation which was much more appropriate than others in finding a balance between protecting people with dementia and enhancing their autonomy and self-determination. To follow up our legal inventory, we received funding from the European disability programme to further analyse existing laws to identify best practices. This culminated in 2001 with the publication of recommendations on how to improve the legal rights of people with dementia. In 2009 and 2010, we updated our existing national reports and developed new reports for the ten new Member States which had joined the European Union in the meantime.

As we revisit the subject again in 2016, I am delighted to see how productive this research has yet again proved to be and how many positive legislative changes we have been able to identify. Whilst previously we had quite a number of legal frameworks that described capacity as an “all or nothing” affair, this is very much the exception today. An important contributing factor to these changes in the approach to legal capacity has undoubtedly come from the important recommendations and conventions produced by the Council of Europe.

Overall, the new mechanisms in place appear to be more flexible and potentially better suited to the evolving needs of people with dementia and their families due to the progressive nature of the disease. I am particularly pleased to observe that these changes are also very much in line with our own 2001 recommendations as well as the position paper we developed in 2009 on the importance of advance directives.

Another positive development is the increasing recognition that the concept of self-determination has received in the legislation. This has been achieved by setting up

mechanisms that allow people to plan ahead and make autonomous decisions whilst they still have the capacity to do so. I am confident that these changes are of great relevance to people with dementia and their families. Everyone should have the right to decide how he/she wants to lead his/her life and a diagnosis of dementia should not change that. Whilst the wellbeing of the person should always be safeguarded, the emphasis should be on empowering rather than on simply protecting the individual.

In this context, it is important to emphasise the relevance and importance of timely diagnosis. Such a diagnosis needs to be disclosed appropriately to the person together with an offer of post-diagnostic support. Information on legal issues such as advance directives or health and financial proxies are an integral part of such an offer.

However positive and promising all these reforms may be, they can only be implemented and maximised if the stigma, myths and misconceptions surrounding dementia, are finally addressed and overcome, and if we (e.g. clinicians, lawyers, judges, researchers, advocates, family members and society in general) are all more open to look at the capacities that the person still has rather than focusing only on his/her limitations. I am therefore encouraged that the changing legal approaches are accompanied in many countries by increasing disease awareness and the development of dementia-friendly initiatives.

In closing, I want to acknowledge the work, enthusiasm and generosity of the many people involved in this report. My thanks go to Ana Diaz, Project Officer of Alzheimer Europe who coordinated this important work and prepared this interesting and thought provoking report with the help of our national member associations and legal experts. A special mention also goes to the members of our European Working Group of People with Dementia who have provided insightful examples of how they have experienced and dealt with some of the legal issues we focused on.

I hope that this report will be of interest to our member organisations and campaigners wishing to promote a human-rights approach to dementia, but also for policy makers interested in reforming their legal systems to better promote the rights of people with dementia.

**Jean Georges**  
Executive Director  
Alzheimer Europe



## 2. Introduction

### 2.1 Background to the report

This comparative report on decision making and legal capacity in dementia has been produced as part of the 2016 Work Plan of Alzheimer Europe (AE), which has received funding from the European Union in the framework of the Health Programme.

The 2009 and 2010 AE Dementia in Europe Yearbooks were dedicated to the topic of healthcare, decision making and legal capacity in dementia<sup>1</sup>. The current comparative report is based on an update of information of some selected sections from these Yearbooks. Agreement on the specific sections to be included for each area was reached at a meeting with 17 AE member associations at the beginning of 2016. The initial plan of work was also presented to the European Working Group of People with Dementia (EWGPWD)<sup>2</sup>.

All members of AE were invited to participate in this report. In addition, relevant informants were identified and approached in countries where AE has no members (i.e. Latvia and Lithuania). A national report for each country was completed by the national Alzheimer association<sup>3</sup>, in some cases with the aid of relevant national experts in the field of social policy and law<sup>4</sup>. A first draft of the comparative report

was drafted by AE and circulated among all participating countries. Any feedback to this first draft was incorporated in the final comparative report. The information provided was supplemented with relevant legislation available in English that AE was able to locate on the internet and with other recently published reports on the topic of legal capacity for other groups or conditions. Table 1 summarises the countries that have been included in this comparative report.

Members of the EWGPWD and their carers were invited to share their experiences with and views on each of the topics addressed in the report by providing a short written testimonial ("personal account"). Four people with dementia and two carers provided personal accounts, which are included at the end of each of the sections of this report. The personal accounts highlight the relevance of promoting the autonomy and self-determination of people with dementia in any decision making related to matters that affect them. The accounts also provide a powerful insight into the complexities involved in implementing the existing legal measures and the emotional and practical challenges linked to establishing decisions on behalf of a loved one.

Table 1: Participating countries

EU Member States			Non-EU Member States	Countries contacted but not included
Austria	Germany	Poland	Jersey	Estonia
Belgium	Greece	Portugal	Monaco	Hungary
Bulgaria	Ireland	Romania	Norway	Iceland
Croatia	Italy	Slovenia	Switzerland	
Cyprus	Latvia	Slovakia	Turkey	
Czech Republic	Lithuania	Spain		
Denmark	Luxembourg	Sweden		
Finland	Malta	United Kingdom (England, NI, Wales & Scotland) <sup>5</sup>		
France	Netherlands			

<sup>1</sup> AE Dementia in Europe Yearbook (2009) "Healthcare and decision making in dementia" and (2010) "Legal capacity and proxy decision making in dementia". Both reports are available at: <http://www.alzheimer-europe.org/Publications/Dementia-in-Europe-Yearbooks>.

<sup>2</sup> In 2012, AE set up the European Working Group of People with Dementia (EWGPWD), comprised of people with different forms of dementia and of different ages and nationalities, to advise the board of AE (through the Chair of the EWGPWD) and to participate (either as a group or through individual members) in all activities and projects organised by AE.

<sup>3</sup> The relevant experts in the case of Latvia and Lithuania.

<sup>4</sup> Please see section "Acknowledgements" for further details of participants.

<sup>5</sup> In the case of the UK, there are different acts on mental capacity in England and Wales (2005); Northern Ireland (2016) and Scotland (2000). The reader is informed when the information applies to the whole of the UK or to only certain parts of the UK.

## 2.2 Relevance of the topic and layout of the report

We all make decisions as part of our daily lives, and often, we can take for granted the right to make such decisions. Decisions may be related to our everyday lives, as for example what a person may want to wear, eat or drink, but also to some other more complex matters as, for example, healthcare treatments, finances, or about selling or buying a property. Some decisions, whilst not necessarily complex, can have a great impact on the life of the person, for example where a person wants to live or with whom a person may want to have a relationship.

In Europe, adults are presumed to have the capacity to make all such decisions. This is within their right to self-determination which is grounded in the value of human dignity (Bioethics committee of the Maltese Department of Health, 2010). However, due to different circumstances, some adults may experience difficulties in making some decisions autonomously. Whilst a diagnosis of dementia, on its own, should not be considered as preventing people from making decisions, its symptoms may, at some times, make it more difficult for the person to understand the information, retain it or communicate his/her decision to others.

Many people with dementia are well able to make decisions about several aspects of their lives, and some, may need at times, support for making or communicating a decision. As the condition progresses, decision making about complex matters, may become challenging.

Traditionally, legislative frameworks aimed to protect people who were considered as lacking the capacity for making decisions on their own, also sometimes to protect the family from decisions by people whose capacity could be questioned. Many jurisdictions in Europe, in the past, had an “all-or-nothing” approach, resulting in the person lacking capacity being deprived of his/her legal rights and the powers given to a substitute (or surrogate) decision maker. This was often based on the assumption that the person was incapable of making decisions or on the paternalistic idea that the person might make ‘bad decisions’ (Mental Disability Advocacy Centre, 2013).

This approach has several limitations. Informal carers are often assumed to know what the wishes and preferences of the person with dementia would have been if the person still had capacity. However, whilst this assumption may be valid in many cases, some studies looking at surrogate decision making in dementia have often revealed other realities (Black et al., 2009). In addition, some carers find making health-related decisions for the person they care for stressful (Denning et al., 2016).

Another challenge related to this approach is that a label of incompetence may become a “self-fulfilling prophecy”. Once individuals are regarded as lacking capacity, they may no longer be addressed by others as the “primary masters of their own lives”, and thus not allowed to make or not involved in making decisions about their lives. This may “contribute to the risk of stereotyping, objectification, and other forms of exclusion which people with disabilities disproportionately face, which in turn adds to the experience of powerlessness and the vulnerability to abuse and neglect” (Commissioner for Human Rights, 2012:12).

Recently, there has been a shift from this caring/ protectionist approach to an approach that has focussed on the principle of self-determination and on promoting the autonomy of individuals so as to enable them to make their own decisions. Article 12 of the United Nations Convention on the Rights of People with Disabilities (UN CRPD) has provided for a paradigm shift in thinking on legal capacity as it “acknowledges that a person may require support to exercise their decision making ability, and that the provision of such support does not make the person a non-person before the law” (Centre for Disability Law & Policy NUI Galway, 2014:10). Similarly, the initiatives of the Council of Europe have helped to promote the self-determination and autonomy of people lacking capacity. Protecting the individual from any potential abuse or neglect and safeguarding his/her wellbeing, are also at the heart of these international conventions and recommendations, but they give greater emphasis to enabling and supporting the person and promoting his/her autonomy.

This shift has resulted in several reforms at national level across Europe where guardianship laws have been downsized and greater emphasis has been given to augmenting individuals’ capabilities instead of thinking of people in terms of “deficits” or focussing on their lack of ability to make decisions (Centre for Disability Law & Policy NUI Galway, 2014). Examples of this could include the provision of support to people who experience difficulties in decision making and also the establishment of mechanisms that allow the person to plan in advance at the time they still have capacity. Another relevant aspect is the key role that has been given to the values, wishes and preferences of the person (as opposed to the best interest approach) and the efforts to involve the person who lacks capacity, as much and for as long as possible, in the decision-making process.

This yearbook looks at some of these aspects and, in particular, how living with dementia may affect decision making and legal capacity. The first part of the report, addresses the topic

of legal capacity as a complex and not unitary concept, and provides an overview of how legislation regulates the issue of legal capacity in questions such as contractual capacity, testamentary capacity, criminal responsibility, civil responsibility, marriage and political rights (i.e. the right to vote). The report then moves on to the topic of informed consent and refers to the existing legal provisions in each country for

people who are not able to provide consent. This section, also provides an overview of the role of advance directives and healthcare proxies. The last section of the report, introduces the topic of substitute (or surrogate) decision making and provides an overview of the different guardianship measures across Europe. It focusses, in particular, on court-appointed guardians and lasting powers of attorney.

## 2.3 Personal accounts



### Alv Orheim, member of the EWGPWD

A few years ago, I accepted grudgingly some of the main implications of my own development of dementia. Through months, my family and close friends had observed more and more memory-slips, missing appointments etc. My final acceptance of the “condition” required two mental stages: a) From now on, you may never rely on just your own judgment. b) On the other hand, it is not the end, not even the beginning of the end.

Thanks to Berit, and other family members, and in particular our grandchildren, I adopted a fighting spirit: Keep going as usual. Take on responsibilities as before, but never deny your mental restrictions, i.e. don’t mislead anyone to expect too high “performance” from you.

To me, the condition has involved an entirely new approach to daily life: Berit has to keep track of every activity and to implement all decisions. I am eager to partake, however my involvement often makes issues messier, and the need for her as “family executive” is confirmed every day.

When looking ahead, our primary approach has been to avoid as much uncertainty as possible. I have had to accept that life consists of several difficult decisions beyond me. Thus, I have to leave them to her. On the other hand, my experience confirms that I am (we all are) capable to “fight” back an unavoidable outcome. Physical exercises, participation in social activities and an open minded “approach” from the public in general, shall always help to keep me alert.

### Berit Orheim, Alv’s wife

This topic presents us with some difficult dilemmas we meet up with when faced with dementia, both as a patient and as a carer. Yet, as long as the person with dementia is functioning well enough, these are also dilemmas which actively or subconsciously are set aside, maybe for as long as possible.

One challenge is to decide what kind of arrangements should be made, for instance a written statement that gives me as a carer the right to insight into my husband’s medical record, or setting up an account which allows just me as a carer to handle family finances.

Another challenge is finding the best time for suggesting such agreements. Is it when the functioning is still good and these provisions may seem less of a threat or a downfall? Or is it when my spouse struggles with coping and may feel relieved to have new arrangements made? Or when he may no longer be aware of his disability to cope, so that matters force themselves? And am I as a spouse always the best person to judge the when and how and what?

I want for my spouse to have him experience autonomy and be part of decision making relating to personal or family matters the way he used to for as long as possible.

So far, things have worked out well. This period of calm could be a good time to discuss these matters. Yet what prevents me as a spouse and carer from initiating such a discussion is a feeling of betraying or “writing off” my husband, of giving in to his illness at a time when there is still so much positive in our lives.

Taking over decision making for a person with dementia, or neglecting to do so at the proper time, hold very serious implications. At present I have no clear answers or strategy, but welcome this opportunity to put into words some of my thoughts on the topic.



# 3. The concept of legal capacity

Legal capacity can be described as “a person’s power or possibility to act within the framework of the legal system” (Commissioner for Human Rights, 2012:7). This is a legal concept that applies to most people of majority age giving the person “the right to access the civil and juridical system and the legal independence to speak on one’s own behalf”<sup>6</sup>. For example, entering into a contract is an

exercise of legal capacity, and so is giving or refusing consent to medical treatment.

Legal capacity is fundamental to a person’s freedom and self-determination and is indispensable for the exercise of civil, political, economic, social and cultural rights (Committee on the Rights of Persons with Disabilities, 2014).

## 3.1 Key international conventions and recommendations

A number of initiatives of the Council of Europe and the United Nations Convention on the Rights of People with Disabilities (UN CRPD) have specifically addressed the topics that are of interest to this report. The following conventions, recommendations and resolutions are particularly relevant to the issue of decision making, consent and legal capacity:

- Convention for the Protection of Human Rights and Fundamental Freedoms: The European Convention on Human Rights (ECHR), 1950, Council of Europe.
- Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: The Convention on Human Rights and Biomedicine, 1997, Council of Europe.
- Recommendation N° R (99) 4 on principles concerning the legal protection of incapable adults, 1999, Council of Europe.
- Recommendation CM/Rec (2009) 11 adopting principles concerning continuing powers of attorney and advance directives, 2009, Council of Europe.
- Resolution 1859 and Recommendation 1993 on protecting human rights and dignity by taking into account previously expressed wishes of patients, 2012, Parliamentary Assembly of Council of Europe.
- The Hague Convention on the International Protection of Adults, 2000.
- United Nations Convention on the Rights of People with Disabilities, (CRPD), 2006, United Nations.

The ECHR and the Convention on Human Rights and Biomedicine, are relevant to the issue of informed consent. Article 8 of the ECHR (“right to respect for private and family life”) protects against unjustified interference with personal integrity. The European Court of Human Rights has made clear that article 8 is applicable to the issue of consent to medical treatment. Furthermore, the Convention on Human Rights and Biomedicine sets out the conditions under which an intervention can be carried out

on a person who does not have the capacity to consent, highlights that a person’s previously expressed wishes relating to medical interventions should be respected, and establishes the conditions under which research can be carried out on people who are unable to consent.

Recommendation N° R (99) 4 and Article 12 of the CRPD (“Equal recognition before the law”) are key to the recent law reforms and modernisation of the concept of legal capacity. According to the Recommendation, the scope of legal protection should be proportional to the person’s actual needs and circumstances, entail a maximum preservation of the protected person’s autonomy, promote the interest and welfare of the person and be respectful of his/her wishes and preferences. Article 12 stipulates that persons with disabilities shall enjoy legal capacity on an equal basis with others in all aspects of life. Accordingly, countries shall take the appropriate measures to provide access to the support people with disabilities may require in exercising their legal capacity and effective safeguards to prevent abuse. This support refers to a range of decision-making arrangements, all of which have at their core the will and preferences of the individual (Flynn and Arstein-Kerslake, 2014b:124). Both the Recommendation and the Convention, ask that the European legal systems of absolute incapacity and general guardianship should be reformed following this philosophy with the aim of permitting the persons concerned to have autonomy in the measure possible, which preserves their dignity and their quality of life.

Recommendation CM/Rec (2009) 11, Resolution 1859 (2012) and Recommendation 1993 (2012) emphasise the need to put in place mechanisms that could promote the self-determination of people who lack capacity. In particular, they recommend that Member States promote the implementation of lasting powers of attorney and advance directives. The recommendations laid down a number of principles to guide Member States in regulating them.

<sup>6</sup> Explanatory Note on legal capacity and forced interventions, accessed online June 2016, <http://www.un.org/esa/socdev/enable/rights/ahc8docs/ahc8idc1218ex.doc>

The Hague convention is an attempt to create a coherent mechanism to enable the cross border protection of adults and their property when they are not in a position to protect

their interests. It promotes the reciprocal recognition of proxy decision-making orders between countries and establishes mechanisms for cooperation between them.

### 3.2 Mental capacity and legal capacity

It is important to distinguish between the concept of mental capacity and legal capacity. Legal capacity refers to the recognition of a person as a holder of rights and obligations before the law. It involves the possibility to create and terminate legal relationships with others (Arstein-Kerslake and Flynn, 2015).

Mental capacity, on the other hand, refers to the ability of an individual to make decisions. The mental capacity of an individual may vary depending on different factors such as the environment, level of education, personality,

health, impairments, etc. (Arstein-Kerslake and Flynn, 2015). Some people may be considered capable of making some decisions but not others that are more complex, or their capacity may change. For example, a person with dementia may be capable of making a decision in the morning when he/she is not tired but not in the evening or when tired. A person's capacity can also be temporarily affected by shock, confusion, fatigue or medication. Likewise, the degree of accessibility of the information provided, the context and other environmental issues, may also greatly influence the capacity of a person for making a decision.

### 3.3 Assessment of mental capacity

There are different approaches to the assessment of mental capacity. Flynn and Arstein-Kerslake (2014a) refer to the status, outcome and functional approach.

Under the status approach, an individual is denied legal capacity based on his/her status as disabled. In this system, there is a presumption of incapacity that is generally predicated on a medical diagnosis of impairment. Under the outcome approach, an individual's legal capacity is denied or restricted based on the perception that the individual has made a poor decision. This approach is outdated as there is a recognition that "we all have the right to make our own mistakes."

Finally under the functional approach, an assessment is carried out to determine whether, at the pertinent time, the

individual understands the meaning and consequences of the decision at issue. The general components of the test are whether the person can use, weigh and retain information in order to make a decision, understand the consequences of the decision and communicate the decision to others. If it is found that the person does not meet the prescribed standard, then the individual's legal capacity is denied (Flynn and Arstein-Kerslake, 2014a:86).

In keeping with the principles of the CRPD (article 12), Flynn and Arstein-Kerslake (2014a) propose the "support model" for legal capacity as an alternative legal response to these approaches. According to this model, legal systems should recognise that "every individual retains legal capacity regardless of the level of support provided, so that a person with a disability is always viewed as a person before

the law” (2014a:102). The model is based on a continuum of support framework (i.e. legally independent, supported and facilitated decision-making) and requires the provision of

enabling conditions which allow the individual to exercise his/her legal capacity (advocacy, alternative communication, advance planning etc.).

### 3.4 Capacity is not a unitary concept

Capacity is not a unitary concept, in fact, there is not simply “one” capacity. Adults have distinct and multiple capacities, including the legal capacity to make a will, to consent to medical treatment, to manage financial affairs or to manage his/her personal affairs.

Each of these capacities involves a distinct combination of functional abilities and skills that sets it apart from other capacities. For example, the cognitive and physical capacities required for driving are arguably distinct from those for making a will.

In addition, each capacity tends to operate in a context specific to itself. For example, the capacity to consent to treatment almost always arises in a medical setting.

The reality of multiple capacities indicates that the operative question should not be “Is he/she competent?” but rather “Is he/she competent to do X in Y context?” In addition, the literature emphasises the relevance of considering, in the assessment of capacity, how the information is provided and in which context. This means that it should be ensured that all practicable help and support to enable the person to make a decision have been given before deciding that the person is no longer capable. So the question from this perspective could be re-phrased as to “how can the person be involved and better supported to make decisions?” (O'Connor and Purves, 2009).

### 3.5 Specific versus general capacity

General capacity is defined as the capacity to manage all one's affairs in an adequate manner. Specific capacity concerns the capacity to perform a specific act. There are many specific capacities recognised by the law.

It is important to realise that different standards, or thresholds, may be applied in determination of either general capacity or a specific capacity: for determination of disability, need for guardianship, etc.

Limited capacity refers to the fact that, within a general or specific capacity, an individual may have the capacity to perform some actions but not others. For example, a person with mild dementia may no longer be able to handle more complex investment and financial decisions, but can still use a chequebook and handle daily sums of money.



## 4. Legal capacity in European legislation

As described in the previous section, legal capacity is not a unitary concept and one can distinguish between different kinds of legal capacities. The following sections provide information on how legislation regulates the issue of legal

capacity in such questions as<sup>7</sup>: contractual capacity, testamentary capacity, criminal responsibility, civil responsibility/liability, marriage and political rights (i.e. the right to vote).

### 4.1 Contractual capacity

Contractual capacity refers to the ability of a party to enter into a legally binding contract. The contractual capacity of an individual is often reduced or abolished, once a legal guardian<sup>8</sup> is appointed for the individual.

In some countries (e.g. Bulgaria<sup>9</sup>, Malta<sup>10</sup>, Portugal and Turkey) a person who is under full guardianship will lose his/her rights to exercise all his/her legal rights, including contracting. In this case, the person can only exercise his/her rights through his/her guardian. Similarly in France, a person under tutorship is continuously represented by the guardian for any civil act.

Often, as is the case for example in Austria, Belgium, Czech Republic, Finland, Germany, Luxembourg, Poland, Slovakia and Switzerland<sup>11</sup>, the judge must determine the limitations to a person's capacity, and/or the acts for which the person will need permission from or the assistance of the guardian, including contractual capacity<sup>12</sup>. This is also the case in the Netherlands, where with the permission of the guardian, the person can enter into legal transactions. In Monaco, "the court may allow an adult under guardianship to perform alone or with the help of the guardian a list of specific acts" (Civil Code). In Denmark, the right to conduct "legal business" can be limited by the State Administration and this can apply to a single aspect or to the person's entire right to conduct legal business. In the case of a guardianship for financial matters, the person can be fully deprived of his/her legal capacity if his/her assets, income or other

financial interests, risk deteriorating significantly or to prevent economic exploitation.

On the other hand, most European legislation contains special clauses that allow contracts, which were made by an individual with a mental disorder at the time of signing the contract, to be voided regardless of whether any system of proxy decision making has been put into place. A general principle is the assumed contractual capacity of an individual, yet at the same time, in most countries, the law allows for contracts to be annulled or voided in case it can be proven that the person signing the contract was mentally incapable at the moment of signing.

Some countries, such as Ireland, Italy<sup>13</sup> and the UK (Scotland<sup>14</sup>), further require that the contract actually resulted in harm to the signatory of the contract. In the Czech Republic, this is also true for people under guardianship. If the person acts without permission from the guardian, the act will only be considered invalid if it has caused harm to the person. No such provision was found in the legislation of Finland, Germany, Greece, Luxembourg and Sweden.

In Italy, Jersey<sup>15</sup>, Lithuania and some parts of the UK, the fact that the other party to the contract was aware of the mental incapacity at the time of signature is a further element that will be taken into account by the courts and will increase the likelihood of the contract being declared void.

<sup>7</sup> Information on consent to treatment and research is presented in section 5.

<sup>8</sup> Information about guardianship measures can be found in section 6.

<sup>9</sup> In Bulgaria, certain transactions, involving the assets of the person under full guardianship, are prohibited or can only be carried out by the guardian with permission from court.

<sup>10</sup> In Malta, three formal measures exist: Interdiction, incapacitation and guardianship (the latter was introduced in 2012, Act No. XXIV). Interdiction and incapacitation are the remit of the Law Courts.

<sup>11</sup> In Switzerland, the limitations to the person's contractual capacity depend on the type of the deputyship (e.g. in a general deputyship, the person's capacity to act is revoked by law).

<sup>12</sup> This does not apply to the Czech Republic.

<sup>13</sup> This only applies to acts involving the disposal of assets.

<sup>14</sup> In Scotland, there would need also to be evidence that the person did not have capacity at the time of entering into the contract.

<sup>15</sup> In Jersey, law of contract is not statutory, and has to be ascertained largely from precedent, i.e. decisions of the Royal Court. Thus there is no certainty what the Royal Court will decide in such a case.

In Lithuania, the person could be required to provide compensation for any expenses incurred by the incapable party, and also for any damage to or loss of the person's property. Similarly, in the UK (England and Wales), a contract entered into by a person who lacks capacity to contract is voidable if the other person knew or must be taken to have known of the lack of capacity. This does not apply if "necessaries" are supplied (Explanatory note of the MCA<sup>16</sup>).

In the UK, people who lack capacity to enter into contracts can incur legal liability for the costs of "necessaries" – i.e. necessary goods and services provided to them by others, and there are informal mechanisms by which others can incur financial obligations on their behalf (Martin et al., 2016:18).

## 4.2 Testamentary capacity

Testamentary capacity deals with an individual's capacity of drawing up a will and bequeathing his/her belongings to another person. The approaches adopted in the different countries with regard to testamentary capacity can be sub-divided into two main groups.

On the one hand, some countries explicitly limit the testamentary capacity of an individual. Thus, in Bulgaria, Croatia, France<sup>17</sup>, Greece, Italy, Lithuania, Luxembourg, Malta, the Netherlands<sup>18</sup>, Norway<sup>19</sup>, Poland, Portugal and Turkey, a person under guardianship covering all aspects of his/her life, is no longer competent to draw up a will.

A will drawn up under these circumstances is automatically deemed invalid. In some countries, such as Croatia and the Czech Republic, guardians are not authorised to make a will on behalf of the person.

On the other hand, in Austria, Belgium, Finland, Germany, Monaco, Spain and the UK (England), a person's testamentary capacity is not automatically withdrawn once a guardianship measure is pronounced by the court. The fact that a person is unable to manage his/her property and affairs does not automatically mean that he/she should be prevented from making a will. Some examples are provided in Box 1:

### Box 1: Examples of testamentary capacity

In Austria and Belgium, the Judge should determine in the guardianship order whether the person still has capacity to make testamentary dispositions. Similarly in Spain, the person retains the capacity to make a will if it was not stated otherwise in the court order.

In Monaco, the Civil Code (article 410–27) states that "adults under tutorship may only write a will when they are capable of expressing free and conscious desires and this must be officially notarised. The person may only withdraw or modify their will under the same condition and form. The notary shall ask testators if they are under tutorship and shall make a note of the answer in the deed".

In Austria and Monaco, if a person is under guardianship by court order, the will has to be made before the court or before a notary. In Spain, in these cases, the notary will require a medical certificate from two different doctors confirming that the person has capacity.

A general criterion for a will to be considered valid is that the person who made it was at the time of "sound mind" or had testamentary capacity. In the UK (England), partial unsoundness of mind is not considered to affect testamentary capacity, unless it actually influences the way the testator disposes of his/her property (i.e. if the person has any mental disorder which would lead him/her to dispose of property and assets differently than he/she would have done were it not for the mental disorder). In addition, the will of an incapable person may still be considered as valid even if it contains an apparently unwise

decision concerning the disposal of property or assets. In this respect, an incapacitated person is granted the same rights as a competent person to make decisions which may seem capricious, foolish, biased or prejudiced to other people. If a person is considered incapable of managing his/her own affairs and of making a will, according to the Mental Capacity Act 2005, a request can be made to the court of protection to draw up a statutory will. The court will obtain medical evidence of the existence of both kinds of incapacity. The person authorised by the court to execute the will, will sign on behalf of the person and with his/her

<sup>16</sup> For further information, please see: <http://www.legislation.gov.uk/ukpga/2005/9/notes/division/6/1/2/6?view=plain>

<sup>17</sup> However, in France and Luxembourg people under curatorship may make a will, and in France, in some cases, the judge may authorise it for a person under tutorship. In France, a person under guardianship can revoke a will before or after the guardianship was established.

<sup>18</sup> This applies only to people for whom a trustee has been appointed, people under mentorship or with a protective will can make a will.

<sup>19</sup> In Norway, a testament drawn up by a person who has been declared legally incapable is invalid unless confirmed by the King.

own name in the presence of two or more witnesses. It is then sealed with the official seal of the court of protection. Such a will is then considered to have the same effect as if the person had been capable of making a valid will.

Generally in all countries, a will can only be contested after the testator's death on the grounds that the person was mentally incapable at the time of drawing up the will. The court will then need to evaluate "a posteriori" the mental capacity of the testator. However, at the time the will is drawn up, the capacity of the person is rarely assessed or confirmed by a doctor. In some cases, if the notary or lawyer considers that the person may lack capacity, he/she must refuse the person's will<sup>20</sup>. This is the case for example of Denmark. In other countries, such as Germany, if a person makes a will with the help of a lawyer, he/she must assess the testator's mental capacity. Without deciding whether he/she has testamentary capacity,

they must simply record any indications they detect of a possible lack of such capacity (§28 Beurkundungsgesetz). In the Netherlands, if a person intends to alter or modify his/her will, the notary must assess the mental capacity of the person. In case of mental incapacity, the notary is not allowed to draw up the will, authenticate or certify an official document on behalf of the person. In Portugal and Switzerland, a will requires the presence of two witnesses<sup>21</sup>. The witnesses have to certify that the person seemed capable of making a will. Finally, in some countries, as for example Latvia, if there are doubts about the capacity of the person, a medical examination is required. In Portugal, according to the Law, the notary is responsible for certifying the capacity of anyone doing any act before him/her. Therefore, if the notary has doubts about the capacity of the person for understanding the meaning and implications of the will, he/she may ask for the presence of a doctor.

### 4.3 Criminal responsibility

Another important aspect of legal capacity is a person's responsibility after having committed a penal offence or crime. Overall, all the legislative systems contain a specific reference to crimes committed by people with a "mental illness" or "mental disturbance". A person can be deemed irresponsible, if at the time of committing the act, due to a disease or mental illness, the person:

- was unable to understand the nature/quality of the act
- did not know that what he/she was doing was wrong
- was unable to refrain from committing the act

In this case, a person cannot be pronounced guilty of the alleged offence. In Ireland, a person can be considered "unfit to be tried" at the start of the trial. In that case, no trial goes ahead. If a trial is held and the person is considered to have actually committed the offence but was insane at the time, it is possible for a verdict of not guilty by reason

of insanity to be reached. In the latter case, a special jury will need to be convened.

In some countries, if the person is deemed as having "diminished capacity", the sentence can be decreased (Finland, France, Italy, Latvia, Lithuania, Monaco, Netherlands, Poland and Switzerland). In Ireland and Jersey, the responsibility of the person can be diminished in the case of murder.

In Luxembourg, if the person is considered as being a danger for herself or others, the person should be sent by the judge to an establishment or service recognised by law as providing the necessary care. In Ireland, the Mental Health (Criminal Law) Review Board's main function is to review the detention of those found not guilty by reason of insanity or unfit to be tried, who have been detained in a designated centre by order of a court. The Review Board must have regard to the welfare and safety of the person whose detention it reviews and to the public interest. The Board is obliged to review each detention at least once every six months.

### 4.4 Civil responsibility

A similar problem as that raised by criminal responsibility is that of the civil responsibility of a person with dementia. This issue deals with the liability of a person and his/her family for material damage caused by him/her.

In France, Luxembourg and Sweden a person can still be liable for damages regardless of whether he/she has a mental disorder.

<sup>20</sup> However, a notary or lawyer is not always required to write a will. In the UK, for example, a person can write the will him/herself, and in certain cases the person is advised to seek legal advice.

<sup>21</sup> In Switzerland, it is also possible to make a holographic will ("testament olographe"), for these wills the presence of witnesses is not necessary. The holographic will is a will which has been completely written, dated and signed by the testator him/herself. The cantons foresee the handing over of the document (either open or sealed) to the appropriate authorities responsible for dealing with such documents.

- In France, according to the civil code a person under guardianship should still “make reparation for any damage that he/she causes”. The person should therefore be covered by personal liability insurance.
- Similarly in Luxembourg, according to the Law of 11 August 1982 concerning Reform of the Law on Incapable Adults (article 489–2) “any person causing injury to a third party while afflicted by mental disorder shall nevertheless be obliged to make reparation.”
- In Sweden, anyone who causes damage whilst under the influence of a serious mental disturbance must pay reasonable compensation, but his/her mental condition will be taken into account, along with other factors, when deciding on the amount.
- In Switzerland, the court may also order a person who lacks capacity to provide total or partial

compensation for the loss or damage the person has caused (special case).

In Bulgaria, the Czech Republic, Germany, Italy, Malta and Switzerland the person may be considered as not liable for damage caused, but the guardian or person responsible for the supervision of the person will be liable. Nevertheless, this would not apply, if this person can prove that he/she had sufficiently carried out the task of supervision or if the damage would have occurred even if proper supervision had been carried out. In Malta, if injured parties cannot recover damages from those responsible for the person who caused the damage, the court may order damages to be paid either partly or in full from the property of the person of unsound mind (article 1036 of the Civil Code).

## 4.5 Marriage

To enter into marriage, it would seem obvious that legal capacity is required. It is therefore interesting to analyse how the legislation addresses this question.

Several legal models are currently in existence and countries seem to differentiate whether some form of guardianship has been established or not. Also, it is interesting to note that, depending on the country, it is either an administrative authority or the family, which is the final “judge” on a person’s legal capacity to marry.

In some countries, regardless of whether a person is under guardianship or not, any person can object to a marriage on the grounds that one of the persons is mentally ill (e.g. Portugal and the UK). In the case of Italy, the marriage can be contested on these grounds.

In some countries (e.g. Belgium, Bulgaria, Czech Republic, Germany, Greece, Latvia, Lithuania, Poland, Portugal, Romania), once a person is under full guardianship, or under partial guardianship if his/her capacity to marry has been limited in the court order, the person is no longer allowed to get married.

In some countries, regardless of the diagnosis of dementia and of the legal capacity of the person, the person can get married if some circumstances are met:

- In Finland, a person always retains the right to marry. However, a person who wants to get married has to understand the meaning and consequences of the

act. The priest/officiator is the person who can make a decision on whether a person has the capacity to get married.

- In Austria, Denmark, Malta, the Netherlands, Norway and Slovakia a person under guardianship can get married with the permission of the guardian or trustee (or of the Court in the case of Slovakia). In Austria and Norway, the person should also be able to understand the duties and responsibilities that it entails.
- In France and Luxembourg, a person who is under curatorship must obtain the consent of the curator in order to marry or, in the absence thereof, that of the guardianship judge. A special clause applies when a person is under complete guardianship (“tutelle”), in which case, a “Family Council” has to agree to the marriage. In France, before a marriage is entered into, the judge must listen to the future spouses. The opinions of the parents and other people with a close relationship with the person also need to be taken into consideration. Similarly, in Monaco the marriage of a person under guardianship must be authorised by the Family Council, especially constituted for this purpose, after interviewing the future spouses and obtaining the opinion of their general practitioner.
- In Turkey, a person with dementia may be able to marry but to do so, the capacity of the person will need to be confirmed by a doctor.
- In the UK, a marriage is valid provided that both parties were mentally capable of understanding the nature of marriage and of consenting to it at the time it was

contracted. As only limited mental capacity is required for the fulfilment of these criteria, the appointment of a guardian does not necessarily affect the right to marry. It is the Registrar of Marriages who must be satisfied that the person concerned understands the implications of the marriage contract. If there is a Deputy in place and a person gets married, if the marriage affects the person's finances then the Court of Protection should be informed.

- In Sweden, the person does not need the permission of the guardian and there is no explicit requirements in the law stipulating that the person needs to understand the significance of the act.

Some countries have provisions that allow for a marriage to be annulled or declared void<sup>22</sup>, in case one of the two partners is found to have been mentally incapable at the moment of marriage. This is the case for Ireland, Italy, Lithuania, Malta, Norway, Poland, Portugal, Switzerland and the UK (England). Such an annulment is only possible within a definite period of time though, with Norway allowing for this eventuality up to 6 months after the marriage, Italy and Ireland a year and England foreseeing a three-year period. In Jersey, a marriage could be declared null and void on the ground 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.

A particular case of annulment is possible in Luxembourg, in case a person under guardianship was not assisted by his/her guardian at the marriage ceremony. Again, such an annulment is only possible up to a year after the marriage.

In some countries, provisions for separation or for getting a divorce exist:

- In Austria, if a person with dementia wants to divorce and his/her legal competence has not been restricted, he/she can file for divorce. If a trustee has been appointed, and the person concerned wanted to divorce before he/she became ill, the trustee is entrusted to file for divorce on behalf of the person.
- In Denmark, a person who wants to get a divorce will need the consent of the guardian.
- In Finland, a guardian can file a divorce case if there is financial abuse from the spouse to the person under guardianship.
- In Monaco, according to the civil code: "After interviewing the requesting spouse and making the observations to him/her deemed appropriate, the president of the Court of First Instance orders, following the request, that the parties appear before him/her for the purpose of conciliation, on the day and at the time he/she indicates. By the same order, the president of the Court of First Instance may, authorise the requesting spouse to occupy a separate residence or to live alone at the marital home (...). Should it appear that the spouse who did not make the request is affected by a mental illness or is unable to express his/her wishes, the president of the Court of First Instance – in the absence of organised guardianship – shall appoint a guardian in charge of assisting the defendant spouse".

## 4.6 The right to vote

A last aspect of legal capacity, which will be studied in this section, is the right to vote of people with dementia. Some countries consider the right to vote as a fundamental right, which cannot be restricted by law or which cannot be restricted for people with a mental disorder. This is the case for Austria, Croatia, Finland, the Netherlands<sup>23</sup>, Sweden and the UK.<sup>24</sup>

However, in other countries (Bulgaria, Greece, Italy, Lithuania, Luxembourg, Malta, Monaco, Poland, Portugal, Romania, Slovakia, Switzerland and Turkey), an individual who is under full or plenary guardianship may not be allowed to exercise his/her right to vote. This (i.e. voting) is typically a type of act for which guardians are not

allowed to act on behalf of the person. Similarly, in Germany, a person who is under guardianship retains the right to vote unless, as stated in the Federal Electoral Law of 1993, he/she is under full guardianship for all matters (i.e. if a guardian has been appointed to permanently manage all his/her affairs). Nevertheless, in these countries, people with dementia can exercise their right to vote if they are not under a guardianship order. Thus, unless the court decided to incapacitate the individual, the person has the right to vote irrespective of whether s/he is cognitively able to do it.

In some countries, the right to vote, for a person under guardianship, may be limited under certain circumstances.

<sup>22</sup> An "annulled" marriage is considered to have taken place and its effects stop at the time of annulment, whereas a "voided" marriage is deemed not to have taken place in the eyes of the law.

<sup>23</sup> Provided that the person is still able to express his/her will and is able to understand the voting procedure.

<sup>24</sup> People retain their right to vote as long as they are able to clearly express their voting choice.

Most often, it is the duty of the judge to determine in the court order whether the person retains the right to vote.

Some examples include:

- In Belgium, Czech Republic, France<sup>25</sup> and Spain a person under partial guardianship (tutorship in France and Spain) retains his/her right to vote unless it is specified otherwise in the court order. In Belgium, France<sup>26</sup> and Spain if there is no mention of it, the right to vote is retained.
- In Slovenia and Portugal, in some cases people under guardianship (partial guardianship in the case of Portugal) can be allowed to vote if the judge considers them as capable of understanding the meaning, purpose and effect of elections.

## 4.7 Personal accounts



**Nina Baláčková, member of the EWGPWD**

I was diagnosed with Alzheimer's disease in 2007 at the age of 49. I have received advice from the doctors in the Czech Alzheimer Society so that I could put in order all of the things that are necessary for the future. Many people know of Alzheimer's disease only as an elderly disease, and only of the last stage of the disease. They don't know about the different stages of the disease and that this disease can affect younger people at about 50 years old.

Because I don't want to cause a problem later on when people have to take care of me, I decided to apply already to a nursing home for people with Alzheimer's which I liked. However it was difficult to find one. Almost all these homes are for people who are older and about 60 to 65 years old.

I have been fighting Alzheimer's for nine years, so I would like to tell my other people with Alzheimer's disease to be active, and as it says in the song "Don't Worry, Be Happy". Even though I know it is difficult sometimes.

<sup>25</sup> In France, Luxembourg, Monaco and Spain, people under curatorship are generally allowed to vote.

<sup>26</sup> However, the person cannot be called to serve on a jury in a criminal court.



### Milja Ahola, wife of Raoul Grönqvist, member of the EWGPWD

In summer 2011, my husband Raoul was diagnosed with dementia at the age of 59. Having to stop working was a shock to Raoul. He sank into depression and needed all his strength to cope with everyday life. Our relationship has always been based on trust and transparency. In financial matters we haven't had disagreements. I started to take care of his affairs. I prepared all the necessary official documents and powers of attorney. Online banking was difficult for Raoul. We agreed that I would have access rights to his bank account. Raoul issued a continuing power of attorney, me

being the trustee. It was not necessary to formally adopt it, as we had had a mutual understanding of everything and so we wanted to avoid unnecessary paperwork. Both of us made testaments and advance directives at the same time. A familiar lawyer verified the documents, which were signed in the presence of two witnesses in February 2013. There were no disagreements in their preparation.

For some time, taking part in the activities of the local Alzheimer association brought meaning to Raoul's life. He also joined the European Working Group of People with Dementia. However his condition deteriorated and I had to progressively become his support and safeguard. I had to take difficult decisions as for example in regards to respite care. Raoul knew very well that I needed breaks and agreed during my leave to stay in a care home. However, when we visited some potential care homes, Raoul did not accept any of them. In the end, our daughter and I had to choose a place we felt would be suitable for him.

In the last year, Raoul's condition has significantly progressed and he has become more confused, to the point where he was taken to the emergency department of the hospital in the middle of the night and we eventually had to ask for his placement in a rehabilitation and evaluation unit. My decision was against Raoul's will. He wanted to come home, but home was no longer safe for him or me. I had to make a decision on his behalf. That wasn't easy. The right to self-determination is a fluid concept when dementia has progressed to a severe stage. If one's safety is threatened, the right to self-determination no longer applies.

Decisions and promises that were made at the early stage of the disease may not be kept at the final stage. No one knows how the disease will progress. Raoul got to live his own kind of life for five years at home. I was not able to fulfil his wish to remain living at home. For that, I am sorry. Now his advance directive obliges me to decide for him. To the best of my ability and strength, I will influence his care and daily life. I am not leaving his life.



# 5. Consent to treatment and research

## 5.1 Informed consent and dementia

### 5.1.1 An overview of the concept of informed consent

The ability to consent to medical treatment, care and/or research is also a specific form of capacity in that it requires certain skills and cognitive abilities. The principle of consent is an important part of medical ethics and the international human rights law. It is a general legal and ethical principle that consent must be obtained before starting medical treatment, providing personal care or involving a person in research. Valid consent must be given voluntarily and freely, without pressure or undue influence being exerted on the person either to accept or refuse treatment or care. There are two main values governing the need to obtain informed consent: 1) to promote and protect the person's wellbeing and 2) respect the person's self-determination (i.e. the desire to make important decisions about one's life oneself) (Alzheimer Europe, 2011).

When talking about consent (to treatment, care or research), it is important to note that it is a question of "informed" consent. Therefore, what is important is that the person consents to something that he/she fully understands and therefore the information should be provided in a way that is according to his/her needs. The explanation should ideally include information about alternatives to the proposed treatment, as well as the implications of the treatment including side effects and possible risks.

According to the Biomedicine Convention, in the case of individuals who lack capacity to consent, an intervention may only be carried out if it is "for his or her direct benefit" and "with the authorisation of his or her representative or an authority or a person or body provided for by law". The individual concerned shall as far as possible take part in the authorisation procedure and any previously expressed wishes relating to the medical intervention shall be taken in to account (extracted from articles 6 and 9 of the Convention).

Similarly, articles 22 and 23 of the Recommendation N° R (99) highlight the need to obtain the consent of a person

who is under guardianship for interventions in the health field provided that he/she is capable of giving it. This reflects the view that people under guardianship should be consulted as far as possible in the decision-making process and that guardianship does not automatically imply total loss of capacity.

### 5.1.2 Consent as a fundamental human right

The right to consent to treatment is also considered as a fundamental right of every human being. This is reflected in the Constitution of many countries. The pertinent articles refer to physical integrity, human dignity, life and personal liberty, and inviolability of the person. In addition, some countries have developed specific laws addressing general patients' rights. It is important to bear in mind, that in some cases, the rights of the patient are lawful (in this case the person can appeal to a court if any of his/her rights are not respected), whereas in other cases, the rights are mainly obligations imposed on healthcare professionals as part of, for example, legally or sometimes not legally binding codes of deontology (Katholieke Universiteit Leuven, 2008)<sup>27</sup>

### 5.1.3 Consent in the case of dementia

Part of the process of obtaining informed consent involves determining whether a person has the necessary capacity. A diagnosis of dementia, or the person's cognitive status, cannot be taken as sufficient proof of their ability to give informed consent (Orwig et al., 2011). Moreover, competence does not equate with perfect rationality (DuBois, 2008). It is generally accepted that a person who is competent for the purposes of decision making has the right to make a decision which other people may consider irrational.

The Nuffield Council of Bioethics (2009) recommends researchers and ethics committees to adapt the information process in a way "to enable rather than to exclude" participants with a cognitive impairment in making decisions.

<sup>27</sup> For further information please see: [http://europatientrights.eu/types/general\\_overview\\_of\\_types\\_of\\_legislation.html](http://europatientrights.eu/types/general_overview_of_types_of_legislation.html).

## 5.2 Consent to treatment

### 5.2.1 Relevant legislative frameworks and codes of medical ethics across Europe

Generally, adults are presumed to have sufficient capacity to decide on and consent to their own treatment or care unless there is significant evidence to suggest otherwise. In the case of adults who are unable to provide consent, most countries have specific laws which dictate how the issue of

consent should be handled. Table 2 provides information on the laws which deal with the issue of consent to treatment in each country. Those marked with a star refer to consent in the case of adults lacking capacity.

**Table 2: The issue of consent in European legislation**

Country	Name of Law	Year
Austria	Federal Hospital Establishment Law (KAG)* Penal Code Commitment Law*	1982
Belgium	Law on patients' right Civil Code Code of Medical Ethics	2002
Bulgaria	Law of Health	Last amended 2016
Croatia	Law of protection of patients' rights	2008
Czech Republic	Health Service Act 372/2011 Civil Code, act 89/2012 Coll.	2011 2012
Denmark	Health Act (LBK No. 1202 of 14/11/2014 )	2014
Finland	Act on the Status and Rights of Patients No. 785*	1992
France	Public Health Code – Code de la Santé Publique Civil Code Code of Medical Ethics	Version 2016 Version of 2013
Germany	Civil Code and Penal Code	
Greece	Law no 3418/2005 Code of Medical Ethics Hospital Act*	2005 1992
Ireland	Mental Health Act 2001 Mental Health Commission Recommendations (for highly invasive treatments) The Assisted Decision-Making (Capacity) Act 2015*	2001 2015
Italy	Constitution Code of Medical Ethics	2014
Jersey	Capacity and self-determination Law Professional bodies standards for professional practice Reference Guide to consent examination or treatment	2016 2001
Latvia	Medical Treatment Law Patients' Rights Law	1997 2010

Country	Name of Law	Year
Lithuania	Law on the Rights of Patients and Compensation for the Damage to their Health Civil Code	1996
Luxembourg	Law on Hospital Establishments Law on patients' rights and obligations Code of medical Deontology	1998 2014 2013
Malta <sup>28</sup>	Patients' Charter of Rights and Responsibilities Mental Health Act*	2012
Monaco	Ministerial Decree no 2012-312 approving the Code of Medical Ethics	2012
Netherlands	Medical Treatments Contract Act (WGBO)* Act on the State Supervision of the Mentally Ill*	
Norway	Act amending the Patients' Rights Act	2009
Poland	Act on Healthcare Institutions Act on Patients' Rights and Patient's Rights Spokesman Penal Code	1991 2008
Portugal	Mental Health Act* Act of the Parliament nº 15/14 consolidating the legislation on the rights and duties of the user of health services Norm nº 015/2013, from the Directorate General of Health Ministry on free and informed consent in therapeutical acts, diagnosis and participation on clinical trials Penal Code	1998 2014 Updated in 2014
Slovakia	Act No. 576/2004 Coll. 2004, Health care Act	2004
Slovenia	Act on Patients' Rights* Law on Medical Practice*	2008 Amended 2014
Spain	Civil Code (art. 1263)* General Health Act* Law 41/2002 regulating patient autonomy and rights and obligations regarding clinical information and documentation	2002
Sweden	Health and Medical Services Act	1982
Switzerland <sup>29</sup>	Constitution Civil Code Law on the protection of adults* (part of the Civil Code)	2013
Turkey	Patients' Rights Act amended 2014 Turkish Civil Law*	2014
UK (England and Wales)	Mental Health Act* Mental Capacity Act*	2007 2005
UK (Scotland)	Mental Health Act (Care and Treatment) (Scot) Act 2003 Adults with Incapacity (Scotland) Act 2000	2003 2000

<sup>28</sup> There is no law in Malta that deals with the consent to treatment issue comprehensively.

<sup>29</sup> There is no patient law on federal level, but the Swiss Constitution and other civil and penal laws are a legal basis for the patients' rights.

Whilst consent to treatment is always required<sup>30</sup>, differences may apply depending on the type of medical treatment that is provided. Some medical treatment, as for example surgery, major interventions, invasive treatments or procedures involving risk or having a known or predictable negative impact on the person's health, always require "explicit" consent, this consent has to be in writing. Examples of this can be found in Austria, Belgium, Croatia, Ireland<sup>31</sup>, Jersey, Portugal<sup>32</sup> and Spain.

Consent to certain treatments, including routine treatment and care, can be oral<sup>33</sup> or "implicit" (as for the example just by turning up for the treatment). In certain cases, treatment can be given without a person's consent. The justification for doing this is that the treatment is "necessary". The concept of "necessity" does not only apply in emergency situations but can justify routine treatment and even simple care. In the UK, if a person lacks capacity to consent to medical treatment, the Mental Capacity Act 2005 states that treatment can be provided if it is in his/her best interests. The Act contains a list of factors that must be considered when deciding whether providing treatment would be in the person's best interests. If there is disagreement, the courts can intervene.

In Scotland, Part 5 of the Adults with Incapacity Act 2000 allows certain medical practitioners to authorise treatment for a person who has been assessed as not having capacity to consent to treatment. They need to complete a specific (section 47) certificate. These powers do not extend to using force or detaining a person in hospital.

In Slovenia, if a person lacks the capacity to consent the doctor can provide basic medical treatment provided that he/she does not or could not know that the person or his/her authorised representative is opposed to the treatment. This would also be the case if the doctor considered treatment to be in the best interests of the patient but was unable to obtain consent within a reasonable amount of time.

Also, differences may apply in the case of some treatments for people with mental health disorders. Some countries have specific provisions for this<sup>34</sup>. The Mental Health Acts, applicable in England, Scotland and Wales, stipulate that consent is not necessary if the treatment is for a mental disorder and the person is detained under the Mental Health Act (with the exception of certain kinds of treatment for which the patients' consent and/or a second opinion is

necessary). In Ireland<sup>35</sup>, as a general rule, medical or surgical procedures may not be carried out without the informed consent of the patient. However, under the Mental Health Act 2001, consent of the person is not required for treatment when, in the opinion of the consultant psychiatrist responsible for their care, the treatment is necessary to safeguard the life of the patient, to restore their health, alleviate their condition, or relieve their suffering and when by reason of their mental disorder, the person is incapable of giving such consent. In all other circumstances consent is required.

### Refusing or withdrawing from treatment

Generally, the person or his/her legal representative, have the right to refuse or withdraw from medical treatment<sup>36</sup>. Such decisions shall be kept in writing in the person's medical file and the doctor should inform the person of the consequences of such refusal or withdrawal. In the Netherlands, in the case of a person who lacks capacity to consent, any non-verbal communication that may suggest that the person does not want the treatment to be continued should be considered.

In Norway, specific provisions exist in the case of a dying patient who is incapable of communicating his/her wishes regarding treatment. In this case, the healthcare personnel may withdraw healthcare provided that the person's next of kin also consents and that the healthcare personnel, based on an independent evaluation, find that this corresponds with the person's wishes.

Some safeguards exist when refusal to treatment can endanger the health of the person or threaten his/her life. In Austria, if a guardian's refusal to treatment would endanger the health of the person, consent to treatment shall be given by the court. In Bulgaria, if the refusal to treatment threatens the life of the person, the chief of the medical establishment can decide to initiate lifesaving treatment. In Finland, a person consenting on behalf of another person, cannot refuse treatment which is necessary to ward off a threat to the life or health of the person.

In Poland and Slovakia, provisions exist for the event of discrepancies on the refusal to treatment. In Slovakia, if a legal representative refuses treatment for a person who is unable to give informed consent, and the physician is of the opinion that such treatment is in the person's best interests, the

<sup>30</sup> However, often, a doctor is legally permitted to administer urgent treatment to an individual who is unable to consent in cases where it is not possible to obtain consent.

<sup>31</sup> In Ireland, in the case of highly invasive treatments such as psychosurgery, in addition to the written consent, authorisation by a tribunal is necessary.

<sup>32</sup> In Portugal, some surgical interventions require the endorsement of two other external doctors.

<sup>33</sup> In Austria, often consent can be oral, however, whilst not always compulsory, written consent is considered a good practice in many hospitals.

<sup>34</sup> Please note that the issue of involuntary internment is beyond the scope of this report.

<sup>35</sup> The Assisted Decision-Making (Capacity) Act 2015 provides laws to support decision making by adults who have difficulty in making decisions without help.

<sup>36</sup> Consideration should also be given to advance refusals, see section on advance directives for further information.

physician has to submit an application to the relevant court to override the legal representative's refusal. In Poland, if the person wants to refuse or withdraw consent to treatment, and their legal representatives or informal carer express opposite wishes, permission to treat the person must be obtained from the Family and Guardianship Court.

## 5.2.2 Who can give consent if the individual is unable to consent? Substitute decision making and self-determination

Typically, if a person lacks capacity to give consent, the "legal representative" can give consent on his/her behalf. For example, if a guardian has been appointed by court, and the guardian has full powers or has been given health care decision-making powers, the doctor must seek his/her consent where it is practicable. Likewise, in countries where health care proxies can be appointed by the person whilst he/she still has capacity to do so (e.g. in a power of attorney for welfare or advance directive), the proxy has the authority to make health and care decisions about the person if the person lacks the capacity to make such a decision.

Some countries have further examples of representatives who can make decisions specifically about health and provide consent to treatment:

- In Austria, if a guardian has not been appointed, it is possible to appoint a next of kin to represent the person or make decisions on his/her behalf for different matters including decisions about treatment and care. The next of kin can consent to treatment which is not expected to have a lasting or serious impact on the person's health.
- In Belgium, a person can, while still capable of understanding, appoint a "mandatary" to exercise rights under the Patients' Law on the person's behalf in the event of subsequent inability of the person to exercise such rights. For this purpose, a special mandate must be drawn up in writing, dated and signed by both the mandatary and the person.
- In Luxembourg, according to the Law on patients' rights (2014) a person with capacity can designate a trusted person ("personne de confiance") for decisions related to his/her health. This document should be in writing, signed and dated.
- In Slovenia, the Act on patients' right allows a person to be appointed to consent or refuse treatment on behalf of the person in the event that the person one day is unable to do so him/herself. This document must be in writing and made whilst the person has capacity.

However, it is important to bear in mind that, in both cases (i.e. guardian or health care proxies), if the wishes of the adult who is unable to consent are known (for example, in a valid advance directive) such wishes should be respected. For example, in Switzerland, a doctor should try to determine if the person who is unable to consent has ever expressed his/her wishes (e.g. in an advance directive) and in principle, any expressed wishes of the person will take precedence over any decision to the contrary made by a legal representative.

Some countries have provisions, for the cases where neither a guardian nor a legal representative have been appointed. In such situations, in some countries, a relative has the authority to consent on behalf of the person who is unable to consent. Some examples include:

- In Belgium, Bulgaria, Denmark, Finland, Greece, Latvia, Lithuania, Malta, Norway, the Netherlands, Spain and Switzerland, some members of the family can provide consent to treatment:
  - In Belgium, Lithuania, Malta and Switzerland, the order of priority of relatives who can provide consent is determined in the legislation. Typically, the spouse (or registered partner) has priority over other family members.
  - In Denmark<sup>37</sup>, Greece, Latvia, the Netherlands and Spain, the person to provide consent should be a close relative but no order of priority is specified in the law.
  - In Bulgaria, the family member who will be able to consent to treatment on behalf of the person shall be designated by the court.
- In addition to family members:
  - In Finland, any person with a close relationship with the person (e.g. a friend) can give consent to treatment.
  - In Switzerland, whilst the cohabiting spouse (or partner) has priority, other people could also provide consent provided that they live with the person who is unable to consent or provide regular support to him/her.

In other countries, whilst a relative or a next of kin, can be consulted, they do not have the right to consent to treatment. In France, for example, in the absence of a legal representative or designated "trusted person", the doctor can consult a family member of, or another person close to, the person who cannot provide consent. However, this is merely for consultative purposes and thus, these people cannot take any medical decisions. Similarly in Monaco, it is stipulated that "where the patient is unable to express his/her wishes, the physician may not intervene without the person's loved ones being alerted and informed".

<sup>37</sup> However, in Denmark, it is not possible to provide treatment against the expressed will of the frail person.

In some countries, if the person is unable to give consent, in the absence of a legal representative, the doctor can decide about the treatment. In Sweden, in this case, the doctor must decide on the appropriate treatment in the light of medical science and proven experience. Similarly, in Scotland, in such situations, a doctor is authorised to provide medical treatment, subject to certain safeguards and exceptions (Adults With Incapacity (Scotland) Act 2000). Other health care staff may also be authorised to provide treatment to an adult who is unable to give consent, as long as the treatment required is within his/her specialism, for example, a dentist<sup>38</sup>. In Denmark, in the absence of a family member who could provide consent, a health care professional can still initiate the treatment if the treatment is endorsed by another external medical expert.

In Norway, both cases (i.e. consent provided by next of kin or by the doctor) may apply. If a person has legal capacity, but is nevertheless unable to give consent, the healthcare provider can decide on his/her behalf for healthcare that is not of a highly invasive nature. In other cases, the person's next of kin may consent on his/her behalf. If the person does not have any next of kin, a healthcare provider may consent on his/her behalf after consultation with other qualified healthcare professionals.

Finally, in some countries, as for example in Poland, if the person cannot consent and does not have a legal representative, consent for the medical treatment has to be provided by the Guardianship Court. In the case of Croatia, in such circumstances, the Social Service shall initiate the process of guardianship specifically for the treatment.

Some of the laws particularly emphasise the need to involve and engage the individual, even when lacking capacity, as far as possible in these decisions:

- In Sweden, under the Health and Medical Services Act, health and medical services shall be conducted so as to meet the requirements for good care. These requirements are described as being founded on respect for self-determination and on the need for care and treatment to be designed and conducted as far as possible in consultation with the person.
- In Denmark, according to the Health Act, the person who cannot consent must still be informed and involved in the discussions to the extent that he/she can understand and that this would not cause injury. This involves taking into account the person's views if they are current and relevant.
- In Finland, according to the Act on the Rights and Status of Patients, a person who cannot consent to treatment due to a mental health problem must nevertheless be consulted, along with his/her legal representative or a person who is close to him/her, before an important decision is made, in order to assess what kind of treatment would be in accordance with his/her will.
- In Switzerland and Slovakia, (according to the Law on the protection of adults and to the Health Care Act respectively) the doctor must ensure that the person lacking capacity is still involved in the decision-making process to the greatest extent possible.

## Box 2: Consent in the UK

Law relating to decision making and consent, particularly in the case of people lacking capacity, varies across the UK. In England and Wales, making decisions about treatment and care for people lacking capacity is governed by the Mental Capacity Act 2005, and in Scotland by the Adults with Incapacity Act 2000. In Northern Ireland, the Mental Capacity Act (Northern Ireland) was passed in May 2016. This provides a decision-making framework for patients who lack capacity. However, it is not clear when this will come into force.

This legislation sets out the criteria and procedures to be followed in making decisions when a person lacks capacity to make such decisions for him/herself. The legislation grants legal authority to certain people to make decisions on behalf of the person. Thus, a person holding a Lasting Power of Attorney for welfare matters (a Welfare Power of Attorney in the case of Scotland) or a deputy for personal welfare, has legal authority to make some or all healthcare decisions for the person. In Northern Ireland, proxy decision-making powers will be available once the Mental Capacity Act 2016 is implemented. If no one has been appointed to make decisions for the person lacking capacity, the doctor must make the decision, after consulting with those close to the person and the healthcare team.

*General Medical Council, online information on consent and UK law<sup>39</sup>*

<sup>38</sup> For further information please see: <http://www.gov.scot/Publications/2008/03/25120154/1>

<sup>39</sup> For further information please see: [http://www.gmc-uk.org/guidance/ethical\\_guidance/consent\\_guidance\\_index.asp](http://www.gmc-uk.org/guidance/ethical_guidance/consent_guidance_index.asp)

## 5.2.3 Advance directives

Advance statement is a general term covering any statement a person may wish to make about future decision making. On the other hand, advance directive is a more specific term relating to particular decisions or types of decisions, particularly regarding medical treatment and health care that may have to be made in the future (Alzheimer Europe, 2009).<sup>40</sup> An advance directive can include:

1. Instructions or requests concerning medical treatment and/or health care; and in some countries
2. A proxy form (sometimes referred to as health care proxy), which lets a person name someone to make decisions about his/her medical treatment or health care on his/her behalf

It is possible but not necessary to complete both parts of the document.

Around one third of the countries participating in this report reported the absence of legislation governing advance directives in their country (Bulgaria<sup>41</sup>, Cyprus, Greece, Italy, Malta<sup>42</sup>, Monaco, Poland, Slovakia, Sweden and Turkey)<sup>43</sup>. However, in some of these countries, such as Cyprus, Greece and Italy, the need to respect the previously expressed wishes of the person regarding his/her healthcare is recognised in the legislative system. In Italy, article 408 of the civil code (amended by law n. 6/2004) allows an individual to appoint a guardian to make decisions on his/her behalf should the person become incapable of doing so. This must be made by a legal notary or written in private and then authenticated. The guardian's duties can be specified and can include decisions related to certain treatments or therapies.

In the remaining countries advance directives have been legislated. Denmark, Finland and the Netherlands were among the first countries in Europe to approve legislation on advance directives. Interestingly, most countries in Europe have introduced legislation on the topic relatively recently (in the last 10 years). See Appendix 1 for an overview of the existing legislation and year of approval in each country.

In term of their scope, in general, an advance directive allows an individual to make an advance expression of his/her

preferences concerning medical treatment which can be relied upon in the event that healthcare decisions must be made at a time when that individual lacks capacity. In almost every country, an advance directive can cover decisions on withdrawal or non-application of life-saving or life-sustaining treatment, refusal of treatment and the prolongation of life. In some countries, such as Germany, Ireland, Latvia, Portugal and Switzerland, the person can specify preferences about any medical investigation, treatment, organ donation (Belgium) or participation in research (for the latter see for example Belgium and Finland). In the UK (England, Wales and Scotland) and in Jersey<sup>44</sup>, advance decisions can be made about specified medical treatments that the person does not want to be given in the future<sup>45</sup>. In Denmark, France, Luxembourg and Slovenia, advance directives contain mainly the wishes of the person in regards to end-of-life care. In Finland, advance directives can contain aspects related to the welfare of the person (e.g. details of the person's preferences regarding food, drink or dressing). In the UK (England and Wales), in an advance statement the person can set down his/her preferences, wishes, beliefs and values regarding his/her future care. However, advance statements are not binding<sup>46</sup>.

In addition, in Belgium, Croatia<sup>47</sup>, Finland, Ireland, Luxembourg, Portugal, Slovenia and Switzerland, it is possible to designate a healthcare representative or proxy in an advance directive. This person will consent to treatment on behalf of the person should the person lack capacity. In Ireland, a healthcare representative has also to ensure that the terms of the advance directive are complied with.

The requirements that an advance directive should meet vary across Europe. Usually, for an advance directive to be valid, the person should be legally competent and free from undue pressure. Also the stated wishes should be legal and applicable to the current situation and proposed treatment. Additional requirements include:

- Involvement of a doctor: In Austria, the person must consult a doctor who should provide information and confirm that the person understands the consequences of the advance directive. In the Czech Republic, the

<sup>40</sup> Alzheimer Europe produced a Position Paper on the use of advance directives in dementia in 2009. For further information on advance directives please visit: [http://www.alzheimer-europe.org/Policy-in-Practice2/Our-opinion-on/Advance-directives/\(language\)/eng-GB](http://www.alzheimer-europe.org/Policy-in-Practice2/Our-opinion-on/Advance-directives/(language)/eng-GB)

<sup>41</sup> In 2016, the Bulgarian government proposed a legislation for Measures of support for individuals, which will regulate advance directives (if the law is approved).

<sup>42</sup> Discussions about the topic are underway.

<sup>43</sup> In Lithuania, advance directives are only possible in the case a person has previously expressed a wish for not to be resuscitated.

<sup>44</sup> According to the new Capacity and Self-determination Law 2016.

<sup>45</sup> Also, carried out or continued by a person providing health care in the case of Jersey.

<sup>46</sup> For further information please see: <http://www.nhs.uk/Planners/end-of-life-care/Pages/advance-statement.aspx>

<sup>47</sup> A new figure has recently been introduced in Croatia: person of trust ("osoba od poverenja"), this person is authorised to consent to or refuse some particular medical procedures on behalf of the person lacking capacity (however not to research) However, this is a new figure in the country and has not yet been fully implemented.

advance directive must also contain in writing the consequences of the healthcare decisions. In Austria and Slovenia, a doctor has to confirm the capacity of the person and sign the advance directive. In Germany, whilst not compulsory, this is also recommended.

- Presence of third parties: In some countries the presence of a lawyer/notary (Austria, Latvia and Portugal<sup>48</sup>) or of one or more witnesses (Austria, Finland<sup>49</sup>, Jersey<sup>50</sup>, Ireland, and the UK – England and Wales<sup>51</sup> and Scotland) can be required.
- In addition, in some cases, to be valid, the advance directive must be in writing (this is true for all countries except Finland, the UK – England and Wales<sup>52</sup> –, and in Austria, for hospitalised patients); signed by the person (e.g. Austria, France, Jersey<sup>53</sup>, Ireland, Luxembourg, Portugal, Slovenia and Switzerland); dated (e.g. France and Luxembourg), and its contents must be unambiguous and the treatment clearly specified (Austria, Jersey, Germany, Ireland, Switzerland and the UK – England and Wales).
- In Denmark, France<sup>54</sup>, Germany, Luxembourg and Portugal there is a Registry for advance directives. In most countries, an advance directive should be kept in the person's medical or care files. In some cases, the person or his/her representative can keep it at home (France for example).
- In Denmark and Switzerland, the doctor must find out if the person has written an advance directive. In Denmark, for this purpose, the doctor must consult the Central Registry.

Another relevant aspect refers to whether advance directives are legally binding. This means that, if an advance directive is available, decisions should be made on the basis of the wishes that were expressed in the advance directive. The

instructions given in an advance directive are thus binding for physicians and for the legal/ authorised representative. In Austria, Denmark, Finland, Germany, Ireland<sup>55</sup>, Luxembourg, the Netherlands, Portugal, Slovenia, Switzerland and the UK (England and Wales) advance directives can be binding, provided they are valid and meet the stipulated requirements. In France, whilst advance directives are not binding, it is considered a good practice to respect the person's wishes as stated in the advance directive. Similarly, in Scotland, advance directives are not legally binding, nevertheless, as one of the principles of the Adults with Incapacity Act 2000 is that the wishes of the adult lacking capacity should be taken into consideration when making a decision on his/her behalf, health professionals should take advance directives into account when deciding on how to treat the person.

In some countries, such as Austria, advance directives can be laid down in binding or non-binding form. Also, an advance directive may only be binding in certain circumstances (e.g. in case of a terminal illness as for example in Denmark and Slovenia, or in the case of refusal to treatment, see for example Ireland).

An advance directive may not be respected if there are "well-founded" reasons for not respecting the wishes of the person. If this is the case, the decision has to be documented in the person's medical file. Appendix 2 provides further information about advance directives by country.

In the majority of the countries, an advance directive has no time limit. In Austria, Portugal and Slovenia, it has to be reviewed every 5 years<sup>56</sup>. In Belgium, an advance directive made specifically requesting euthanasia, in the case where a person is unconscious and has an irreversible medical condition, must have been made in the last 5 years.

## 5.3 Consent to research

Legislation relating to consent to treatment does not generally also cover consent to participate in research. This may be due to the fact that not all research is actually necessary for the health of the participant. Furthermore, participation in various kinds of research often entails a certain degree of inconvenience and/or risk. These issues

are important when considering the participation of people who are unable to consent.

At an international level, a number of international declarations and conventions have been developed to ensure that research is conducted in an ethical manner and that the

<sup>48</sup> However, in Portugal, it is also possible to make the advance directive at the RENTEV (Living Will National Registry).

<sup>49</sup> It is recommended but not obligatory.

<sup>50</sup> For life sustaining treatment.

<sup>51</sup> In case of oral statements. In England and Wales if the person wants to refuse life-sustaining treatment the advance decision must be written down, and the person and a witness must sign it.

<sup>52</sup> In England and Wales although advance decisions are usually written documents, they may also be witnessed oral statements, signed printed cards or discussion notes recorded in patients' medical files.

<sup>53</sup> In case of life-sustaining treatment.

<sup>54</sup> Please see law of 2 February 2016 « Relative aux maladies et personnes en fin de vie » (relative to diseases and end-of-life).

<sup>55</sup> In Ireland, requests for treatment are not legally binding, however treatment refusals are as effective as they would be if the person had capacity.

<sup>56</sup> The Law "Relative to diseases and end-of-life" in France established that advance directives do no longer need to be reviewed, still the person can review or change it at any time.

human rights of the participants are respected. The Nuremberg Code (1947), the Declaration of Helsinki (1964), the UNESCO's Universal Declaration on Bioethics and Human Rights (2005) are among the most relevant ones. Within the European regulatory framework, the European Charter of Fundamental Rights (ECHR) contains several principles which can be relevant in the context of research. Article 3, 7 and 8, emphasise the necessity of (i) obtaining free and informed consent from the person, (ii) respecting the private life of the person and (iii) protecting personal data. Also, the Biomedicine Convention, addresses ethical issues raised whilst conducting research within the framework of human rights and sets common standards for all members of the Council of Europe.

The conduct of clinical trials<sup>57</sup> in humans in the European Union (EU) is regulated through Commission Directive<sup>58</sup> 2001/20/EC (i.e. the "Clinical Trials Directive"). Commission Directive 2005/28/EC lends further support to the Clinical Trials Directive (2001) and lays down principles and rules on good clinical practice (the "GCP Directive"). A new EU Regulation on clinical trials on medicinal products for human use (No 536/2014) has been adopted, but this new regulation has not yet come into effect<sup>59</sup>.

These Directives (i.e. Clinical Trials Directive and the GCP Directive) set the minimum requirements that must be implemented into the national law of each Member State in regards to the conduct of clinical trials. Their content has to be transposed into national law by each of the Member States.

In the Clinical Trials Directive, informed consent is defined as a:

*"decision, which must be written, dated and signed, to take part in a clinical trial, taken freely after being duly informed of its nature, significance, implications and risks and appropriately documented, by any person capable of giving consent or, where the person is not capable of giving consent, by his or her legal representative"* (2001:6)

The Directive also refers to the participation of people who are "incapable of giving legal consent" to clinical trials, stating that such individuals may not be included in clinical trials if "the same results can be obtained using persons capable of giving consent". Specifically, the Directive mentions that the inclusion of "persons with dementia" in clinical trials should be on an even more restrictive basis. Adults unable to consent for themselves, should only be administered a drug tested in a clinical trial, "when there are grounds for assuming that the direct benefit to the person outweighs the risks". In any case, the interests of the individual should always prevail over those of science and society.

The Directive, also highlights the necessity of pursuing, in such cases, written consent from the person's legal representative. Consent from the legal representative should be pursued in line with existing national laws. However, a person who is not able to give informed consent should still "receive information according to his/her capacity of understanding regarding the trial, the risks and the benefits" (2001:9). In regards to the person's wishes, the Directive makes reference to:

- any previously expressed wishes about giving or refusing consent
- the person's presumed will
- if the person is capable of forming an opinion and assessing this information, consideration should be given to his/her wish to refuse participation in, or to be withdrawn from, the clinical trial at any time

Ethics Committees have an important role as they shall consider "the adequacy and completeness of the written information to be given and the procedure to be followed for the purpose of obtaining informed consent".

Table 3 provides information on laws or relevant codes of medical ethics relating to consent to research. Those marked with a star are laws referring to or exclusively addressing clinical trials.

<sup>57</sup> A clinical trial is a biomedical/health-related research study into the effects on humans of a new medical treatment. Before a new drug is authorised and can be marketed, it must pass through several phases of development (trial phases) in which its safety, efficacy, risks, optimal use and/or benefits are tested on human beings. Further details can be found in <http://www.alzheimer-europe.org/Research/Understanding-dementia-research/Clinical-trials>.

<sup>58</sup> Directives form part of the EU's secondary law and are mainly used as a means to harmonise national laws. Once a directive has been adopted at EU level, it is then transposed by EU countries into their internal law for application. However, it is up to each individual country to develop its own laws to determine how to apply these rules.

<sup>59</sup> Although the Regulation was adopted and entered into force in 2014, the timing of its application depends on confirmation of full functionality of the EU portal and database through an independent audit. The EU portal and database should be available for the independent audit by August 2017. If the systems pass the audit, the Regulation will come into effect by October 2018. For further information please visit the link: [http://www.ema.europa.eu/ema/index.jsp?curl=pages/regulation/general/general\\_content\\_000629.jsp&mid=WC0b01ac05808768df](http://www.ema.europa.eu/ema/index.jsp?curl=pages/regulation/general/general_content_000629.jsp&mid=WC0b01ac05808768df).

Table 3: Relevant legislation/codes of medical ethics relating to consent to research

Country	Participation in research	Year
Austria <sup>60</sup>	The Medicines Act 185, 1983 * General Civil Law	Amended in 2010
Belgium	Law on experiments on human beings Code of Medical Ethics Civil Code	2004
Bulgaria	Act on Medicinal Products in Human Medicine*	
Croatia	Family act 103/15* “Law on protection of persons with mental disorders” NN 76/14	2015 2015
Czech Republic	Act 378/2007 Coll. on pharmaceuticals*	2007
Denmark	Act on a Scientific Ethic Committee system and treatment of biomedical research projects LOV 593 /2011 Guardianship Act	2011
Finland	Act 488 on Medical Research*	
France	Public Health Code – Code de la Sante Publique	Version 2016
Germany	Medicinal Products Act and the Ordinance on Good Clinical Practice*	2004
Greece	Hospital Law	1992
Ireland	European Communities (Clinical Trials on Medicinal Products for Human Use) Regulations, SI No 190 of 2004*	2004
Italy	Legislative Decree 211* – Transposition of Directive 2001/20/EC relating to the implementation of good clinical practice in the conduct of clinical trials on medicinal products for clinical use	2003
Jersey	Capacity and Self-determination Law*	2016
Latvia	Convention on Human Rights and Biomedicine Patients’ Rights Law	Ratified in 2010 Since 2010
Lithuania	Law on ethics of biomedical research	Revised in 2015
Luxembourg	Regulation on the application of good clinical practice in the conduct of clinical trials of medicines for human use*	2005
Malta	Guidelines relating to consent of patients Data protection Act Patients’ Charter (College of Family Doctors) Subsidiary Legislation 458.43, Clinical Trial Regulations*	Amended 2007
Monaco	Law 1265 on the protection of human subjects in biomedical research	2002
Netherlands	Law Medical-scientific research in humans (WMO)	1998

<sup>60</sup> In Austria, regulations on research involving human beings cannot be found in a statute, they are in a number of single pieces of legislation (Matias, 2012 International Neurolaw).

Country	Participation in research	Year
Norway	Act of Health Research Patients' Rights Act	2008
Poland	Pharmaceutical Act* Regulation on good clinical practices – Ministry of Health 2012	2001 2012
Portugal	Act of the Parliament 21 N° 21/2014 of 16.04 on the conduct of clinical trials on medicinal products for human use and medical devices* Mental Health Act	2014 1998
Slovakia	Act No. 576/2004 Coll. 2004, Health care Act	2004
Slovenia	Drug Act (No. 31/06) and Bylaw on Clinical Trials (No. 54/06)* The Code of Medical Deontology	2006
Spain	Law 14/2007 on biomedical research Decree 1090 regulating clinical trials with medicinal products, Ethics Committees for Investigation with medicinal products and the Spanish Clinical Studies Registry*	2007 2015
Sweden	Act on ethical review of research involving humans	
Switzerland	Federal Act on research involving human beings Clinical Trials Ordinance*	2014 2014
Turkey	Patients' rights Act	
UK (England and Wales)	Mental Capacity Act <sup>61</sup> Medicines for Human Use (Clinical Trials) Regulations (CT Regulations)*	2005 2004
UK (Scotland)	Adults with Incapacity (Scotland) Act (AWIA) <sup>62</sup> Medicines for Human Use (Clinical Trials) Regulations (CT Regulations)*	2000 2004

In summary, according to the Directive, the wellbeing of the participant should always be paramount. Consent is always necessary, it should represent the presumed will of the person, and even if the person is unable to give consent, the person should be provided with information that is adequate to his/her needs and should be involved as much as possible in the process. The next sections further explore who can consent on behalf of the person when the person is unable to and the specific situations where the person lacking capacity cannot take part in research.

In all countries (except Croatia), if the person is under guardianship (either full or partial, in the latter, provided that the guardian has been given this power) the guardian can consent to participate on behalf of the person<sup>63</sup>.

In Croatia, according to the Family Act (2015) and to the Law on protection of persons with mental disorders (2015), guardians are not allowed to consent to biomedical research<sup>64</sup> on behalf of the person with dementia. In Slovakia and Switzerland, the guardian can provide consent to participate in research if the research involves low or minimal risk and burden to the person who lacks capacity.

Similarly, any other legal representative who has been appointed in advance by the person (e.g. power of attorney or health care proxy) can give consent to participate in research. As in the case of consent to treatment, in Belgium, Denmark, Finland, France, Netherlands, Norway and Switzerland, in the absence of a legal representative, a member of the family, typically, the spouse or an adult

<sup>61</sup> The MCA in England and Wales does not apply to Clinical Trials of Investigational Medicinal Products. The arrangements for adults unable to consent for themselves are covered specifically in the legislation for clinical trials. For further information please visit: <http://www.hra.nhs.uk/resources/before-you-apply/consent-and-participation/adults-unable-to-consent-for-themselves/#sthash.zuJiTeOf.dpuf>

<sup>62</sup> The AWIA in Scotland does not apply to Clinical Trials of Investigational Medicinal Products. The arrangements for adults unable to consent for themselves are covered specifically in the legislation for clinical trials. For further information please visit: <http://www.hra.nhs.uk/resources/before-you-apply/consent-and-participation/adults-unable-to-consent-for-themselves/#sthash.zuJiTeOf.dpuf>

<sup>63</sup> In Belgium, in the guardian order it has to be expressly stated whether the person retains or not his/her right to consent to participation to research.

<sup>64</sup> Including clinical trials.

child, can consent on behalf of the person to research participation. In Finland and France, there is an emphasis on the relationship between the person and the person consenting rather than a family tie (i.e. any closely related person in Finland and a trusted person “personne de confiance” in France). In Monaco, consent to participate in research has to be given by the guardianship judge, the family council or the legal representative.

In some countries, such as Austria, Denmark, Germany and Ireland, people who have been institutionalised or are in forced internment, are not allowed to participate in research<sup>65</sup>.

Similar provisions can be found in the Law on forced internment of Luxembourg, where on the contrary, it is possible to administer certain kinds of treatment which are not yet fully recognised by medical science or which entail a certain degree of risk subject to the approval of committee of

experts. The clinical testing of medical products or techniques which are relevant to the person’s psychiatric therapy is also possible in Luxembourg subject to authorisation from the Minister for Health.

In the UK (England and Wales) the issue of consent to research is different, as there is no specific law on it. In Scotland, there are provisions in the Adults with Incapacity (Scotland) Act 2000 regarding research and guidelines have been issued by the Law Commission. In Jersey, according to the new Capacity and Self-determination Law (2016) the States of Jersey may make provisions as to the extent and circumstances in which it may be lawful to conduct intrusive research involving a person who lacks capacity to consent to research. Medical treatment, examinations or observational research, involving a person who has not provided his or her consent, will amount to an interference with private life (explanatory note of the Law, 2016).

## 5.4 Personal account



**Hilary Doxford, member of the EWGPWD**

Dementia adds an additional layer of complexity to all aspects of dementia research whether it be engaging patients in the research cycle or as an active participant in a research study or drug trial. Over the last three years I have been involved in one clinical trial and at least eight non clinical research studies. Without exception, the consent mechanisms have been clear, followed to the letter and given me no cause for concern. Having said that I am in the early stages of dementia and still have sufficient cognitive ability to make decisions for myself. Once I hand over decision making to my husband, I already know that he is unlikely to consent to me signing up

to any study considered ‘high risk’. My counter-argument is that if I am now at a stage where I am incapable of making decisions, do not dismiss any request without an in depth analysis of whether it may help me. By that stage, doing nothing means the inevitable outcome and I would not want to rely on other brave people putting themselves forward in effect on my behalf.

What a dilemma for the person you love. I haven’t done it yet, but I am going to write some very clear guidelines on my wishes for my husband to follow. It is not fair for me to ask him to make these decisions on my behalf. If our roles were reversed I don’t think I could make these decisions on his behalf. I know I would not want to expose him to unnecessary risk, pain or harm, but someone has to do it. In that situation I would want to know his thoughts.

All I ask is that researchers conform to whatever legislation and good practice is in effect at the time and my husband carries out my wishes. What more could I ask for?

<sup>65</sup> In the case of Ireland, in particular, in clinical trials.





## 6. Systems of substitute decision making

This last section of the report provides information on systems of substitute decision making by reviewing the existing legislation and provisions across Europe applying to court-appointed decision makers and to powers of

attorney. The terminology used across Europe for this is very diverse<sup>66</sup>. For this reason, for the purpose of this report, the generic term “guardianship” will be used.

### 6.1 Court appointed decision-makers (guardianship)

#### 6.1.1 The legal framework

Table 4 below shows the relevant legislation for guardianship and supported decision making in each of the participating countries. Interestingly, more than one third

of the countries included in this report have amended or modernised their legislation in the last five years.

Table 4: Sources of legislation

Country	Relevant legislation on guardianship and supported decision making and amendments	Year
Austria	Civil Code 136th Federal Law on Guardians for Disabled Persons	1983
Belgium	Civil Code Law reforming legal incapacity regimes and introducing a new protection status that is consistent with human dignity (Loi réformant les régimes d'incapacité et instaurant un nouveau statut de protection conforme à la dignité humaine)	2014
Bulgaria	Law for the Persons and Family Code of Civil Procedure (CCP)	Amended 2002 2008
Croatia	Family Act	2015
Cyprus	Administration of the property of Incompetent Persons Law	1996
Czech Republic	Civil Code Special judicial proceedings act	Amended 2012 2013
Denmark	Guardianship Act No 1015	2007
Finland	Guardianship Services Act 1998	1998
France	Civil Code Law on the legal protection of vulnerable adults (Act No.2007-308) Decree No 2015-1288 on the simplification and modernization of family law (“Simplification et modernisation du droit de la famille”)	2007 2015
Germany	Civil Code Custodianship Act	Amended 2009 1992

<sup>66</sup> For example: curator, tutor, trustee, mentor, deputy, etc.

Country	Relevant legislation on guardianship and supported decision making and amendments	Year
Greece	Civil Code Civil Procedure Code	
Ireland	Assisted Decision-Making (Capacity) Act	2015
Italy	Civil Code Law No. 6 «Amministrazione di sostegno »	2004
Jersey	Mental Health Law Capacity Policy and Procedures Capacity and Self-determination Law	2015 2015 2016
Latvia	Civil Law	Amended 2012
Lithuania	Civil Code	Amended 2011
Luxembourg	Law on legally incapable adults	1982
Malta	Civil Code ACT No. XXIV to amend the Code of Organization and Civil Procedure and the Civil Code for the purpose of providing for Guardianship Mental Health Act <sup>67</sup>	2012 2012
Monaco	Civil Code	
Netherlands	Civil Code	
Norway	Guardianship Act	1927
Poland	Family and guardianship code Civil Code Code of Civil Procedure	1964 1964 1964
Portugal	Civil Code Code of Civil Procedure	
Romania	Civil Code Mental Health Law of 2002	Amended 2009 2002
Slovakia	Act No. 161– The Civil Proceedings Code for Non-adversial Proceedings	2015
Slovenia	Civil and Family Code	
Spain	Civil code	
Sweden	Constitution Code on Parenthood and Guardianship (amended 2005)	
Switzerland	Civil Code (Law on the protection of adults)	Amended 2013
Turkey	Civil Code	
UK: England & Wales	The Mental Capacity Act 2005	2005
UK: Northern Ireland	The Mental Capacity Act (Northern Ireland)	2016
UK: Scotland	The Adults with Incapacity (Scotland) Act – AWIA	2000

<sup>67</sup> The Mental Health Act in Malta allows for the appointment of a curator who, however, has limited capacities with the main role being supportive rather than linked to decision-taking.

## 6.1.2 Understandings of capacity

Whilst many countries have now modernised their legislation, differences still exist. In some countries, like for example Portugal, capacity is seen as an “all or nothing” phenomenon and it is not assessed according to the person’s concrete needs or to the different categories of acts (i.e. make a will, drive, choose the place to live, financial or property decisions). Article 138<sup>68</sup> of the Civil Code in Portugal, states that if a person has a mental health problem (or has a hearing, visual or speech impairment), which makes it impossible for him/her to be held responsible for people or property, the person can be prohibited from exercising his/her rights (i.e. subject to interdiction).

In contrast, some countries (e.g. Ireland, Jersey and the UK)<sup>68</sup> have taken a decision-specific and functional approach<sup>69</sup> to capacity. This means that “a person cannot be said simply to be incapacitated or to lack capacity but they must lack mental capacity in relation to particular action(s) or decision(s) at the particular time in question” (Martin et al., 2016:19). Accordingly, a person is considered to lack capacity to make a decision if he/she is unable to understand, retain, use or weigh up the information or communicate the decision. A person may then lack capacity in respect of a decision on a particular matter at a particular time, but this does not prevent the person from being regarded as having capacity to make decisions on the same matter at another time or on other matters.

The legislation in Ireland and the UK (England, Wales and Northern Ireland), also enable the individual to make his/her own decisions, without the quality of the decision being viewed as an indicative reflection of capacity. “Unwise decisions” should not be used as indicators of a lack of capacity— i.e. people with impairments should be entitled to take risks and to make poor decisions. Similarly in Jersey, lack of capacity cannot be established by reference to “a person’s condition, or an aspect of a person’s behaviour, which might lead others to make unjustified assumptions about the person’s capacity”.

In Ireland, Jersey and in the UK the legislation provides for the provision of support to a person before it can be said that the person lacks capacity. In Scotland, for example, according to the Adults with Incapacity (Scotland) Act 2000, an adult cannot be deemed to be incapable of making a decision by reason of an inability to communicate if it can be overcome by any other means, human, mechanical or interpretive. The new Mental Capacity Act in Northern Ireland, provides a very concrete explanation of the

“practicable steps” that should be taken prior to any determination) that the person lacks capacity:

- The provision to the person, in a way appropriate to his or her circumstances, of all the information relevant to the decision. This should include information on the foreseeable consequences of deciding one way or another; or failing to make the decision.
- Ensuring that the matter is raised with the person at a time and in an environment likely to help the person to make the decision, and that the persons who are likely to help the person to make a decision are appropriately involved.
- For the purposes of providing the information in a way appropriate to the person’s circumstances it may, in particular, be appropriate to use simple language or visual aids; or to provide support for the purposes of communicating the information or explanation.

## 6.1.3 Degrees of deprivation in the different national legal frameworks

Traditionally, there have been two models of deprivation of legal capacity, namely full (or plenary) guardianship and partial guardianship. Under a full guardianship order, the person would be deprived of all his/her rights to self-determination and the guardian is granted comprehensive decision-making authority over an individual’s financial affairs or personal care or both. Thus, a person under full guardianship may lose all fundamental rights including the right to manage his/her finances, buy or sell property, make decisions about their health care or the place where they want to live, get married, vote in elections, etc.

In the case of partial guardianship, the powers and duties that are granted to the guardian are limited. A person under partial guardianship retains some rights depending on his/her level of capacity. Still, there are differences in these partial systems, as in some cases, the judge has flexibility to decide, on a case by case basis, from which rights the individual is deprived or needs assistance for. This means that in some cases a person placed under partial guardianship will still be able to exercise the right but will need the assistance of the guardian or to act jointly with the guardian for the act to be considered valid, and in other cases, the person may lose the capacity to exercise the specific right and the guardian will represent the person. However, for any other right not included in the Court Order the person retains the possibility to exercise the right.

<sup>68</sup> Assisted Decision-Making (capacity) Act 2015 (Ireland), Capacity and Self-Determination Law 2016 (Jersey), Mental Capacity Act 2005 (England and Wales), Mental Capacity Act 2016 (Northern Ireland), Adults with Incapacity (Scotland) Act 2000.

<sup>69</sup> In the UK the functional approach is combined with a diagnostic threshold, giving rise to what is referred to as the ‘two-stage test of capacity’.

### Box 3: Full and partial guardianship measures in Finland

In Finland, the legal capacity of the individual can be limited in different ways. The court may restrict the legal capacity of the person by allowing him/her to carry out particular legal acts or manage particular assets jointly with his/her guardian/s, or, on the other hand, may restrict the legal capacity of the person concerned for these acts, and thus, the person will not have the legal capacity to carry out these particular legal acts. Finally, if the person is declared legally incompetent, it means that he/she “cannot self-administer his/her property or enter into contracts or other transactions, unless otherwise provided elsewhere in the law” (2016:23).

*AJuPid (2016) Access to Justice for persons with intellectual disabilities.*

Austria, Germany and Sweden were among the first countries to radically alter their dated guardian or trusteeship laws. Through these reforms the all-or-nothing approach to legal capacity was abolished and a more flexible system established. One of the most relevant changes in the reform of the German Guardianship Law was the separation between appointing a guardian and the declaration of legal capacity to act (Brosey, 2014). In Germany, a person can no longer be “entmündigt”. This word means incapacitated or “declared incapable of managing one’s own affairs”. This term has connotations of the loss of fundamental and basic rights, which are acquired with adulthood. The term “geschäftsunfähig” which is used in §104 of the Civil Code simply means

“incompetent to carry out business” and therefore has fewer derogatory connotations (Brosey, 2014). As explained in the previous section, in the UK (England, Wales, Northern Ireland), the Capacity Acts recognise the need to look at the capacity for each single act, and highlights that lack of capacity for one matter or at a particular time, should not be considered as lack of capacity for other matters or at other times.

Most recently, some other countries have similarly amended their civil codes (Czech Republic, 2014; Latvia, 2013) or passed laws (Belgium, 2014; Croatia, 2015<sup>70</sup>; Slovakia, 2015; Switzerland, 2013) eradicating the forms of plenary<sup>71</sup> guardianship and/or prioritising forms of partly substituted decision making.

### Box 4: Examples of recent amendments/new acts addressing legal capacity

In the Czech Republic, the reformed Civil Code (2014) states: “A court may limit legal capacity in connection with a certain matter for a period necessary to arrange such matter (...) The court shall determine the scope of rights and duties of the guardian” (Section 463 of the Civil Code).

In Slovakia, the recently introduced Act No.161/2015 (Civil Proceedings Code for Non-adversarial Proceeding) does not allow for the complete deprivation of legal capacity. In the Act, it is stated that, if an individual is able to do only certain legal acts, the court shall restrict his capacity to legal acts and shall specify the extent of such restriction in the decision.

In Switzerland, new legislation for legal capacity came into force in 2013. The main principle of the reformed law was to support the person’s right to choose (e.g. advance directives, designation of a health care or welfare proxy). The new law introduced a new measure: deputyship (Curatelle, Beistandschaft). If a person is no longer able to manage his/her own affairs as a result of mental disability, psychiatric disorder or other condition, and the support provided by family members, private volunteers or public services is insufficient, the authorities will be called upon to tailor a support package for that person. They must determine the tasks and roles to be fulfilled by the deputy in accordance with the needs of the person concerned.

In several countries, the legal system foresees the possibility of full and partial guardianship measures. Some examples of this are:

- The legal systems in France, Luxembourg, Monaco and Spain share some similarities. In France, Luxembourg and Spain, the measure of “judicial protection” is used as a measure of protection which applies to a

person who needs temporary protection. Curatorship, on the other hand, is established when a person is not entirely incapable of handling his/her own affairs but needs advice, or to be assisted or supervised in carrying out civil acts. Tutorship<sup>72</sup> applies to a person who needs to be represented in a continuous manner in order to carry out civil acts. A new measure has been put in place in France recently: “habilitation

<sup>70</sup> The Act is relatively new. According to Alzheimer Croatia, there are already several difficulties for implementing it, and certain changes are expected to be made soon.

<sup>71</sup> Or stipulating that full guardianship should be always used as a last resort measure.

<sup>72</sup> In Spain, a person can be under full tutorship (for all acts including finances and the wellbeing and care of the person) or partial tutorship (only for financial affairs).

familiare". This allows a family member or a close friend to represent a person who cannot express his/her wishes in some or all civil acts. This measure only requires a "one-off" intervention of the Judge.

- In a similar vein, in Lithuania, Poland, Portugal and Romania a full guardianship<sup>73</sup> shall be established with the aim of exercising, protecting and defending the rights and interests of a person who is considered as legally incapable for all acts, whereas a less restricted form<sup>74</sup> shall be established with the aim of protecting and defending the rights and interests of a person of limited legal capacity.
- In the Netherlands, three forms of protection exist: full guardianship (curatorship), protective trust and mentorship. The duties of the guardian are determined by the judge at the time of appointment. Once a guardian has been appointed, the adult is no longer competent to enter into legal acts unless the guardian gives his/her authorisation (provided that the guardian has authorisation for such acts). In the case of a protective trust, the duties of the administrator of the protective trust are limited to financial affairs. The duties of the mentor include responsibility for legal dealings in matters related to care and treatment.
- According to Turkish law, depending upon the severity and urgency of the given situation, the court-appointed person may be: (1) for a wide range of daily issues a guardian (vasi), (2) for urgent, specific, temporary issues a curator (kayyim), or in cases of (3) mild mental difficulties a legal advisor (yasal danisman).

Interestingly, in some countries, the legislative system has been reformed, however the new measures co-exist with the previously existing ones:

- In Italy, Law n. 6/2004 introduced into the Italian judicial civil system the rules known as "amministrazione di sostegno". The term describes the procedure which involves the provision of a gradual protective intervention and responds to the specific needs and abilities of the beneficiary. This law, however, did not repeal previous rules of judicial disability (loss of fundamental basic rights which are acquired with adulthood) and judicial disqualification (incompetence to carry out business). So these measures of full and partial guardianships co-exist with this new measure. The law applies to people who are unable to look after their affairs due to major illness or permanent disability. The goal of the new rules is to balance the opposing needs for independence and protection, granting people as much freedom as possible and, at the same

time, ensuring that they are provided with necessary protection that is proportionate to their needs and fair.

- In Malta, the Guardianship legislation, (ACT No. XXIV of 2012) introduced the system of guardianship for those persons who need support to manage their affairs. Since 2014, a Guardianship Board has been created, which regulates how guardianship orders are issued and implemented. Currently three measures exist in Malta: interdiction, incapacitation and guardianship. The Law Court of Voluntary Jurisdiction decides in the case of Interdiction and Incapacitation. With regard to guardianship, the Guardianship Board takes a decision and when deemed appropriate, appoints one or several guardians. Interdiction and incapacitation orders can be converted to Guardianship orders through a request to the court. If there are insufficient grounds for the conversion to be made, the interdiction or incapacitation remains in force (Cacciottolo, 2016).

Both approaches to guardianship presented in this section (plenary and partial systems) mostly imply substituted decision making<sup>75</sup>. Some of the newest legislation have taken a different approach (e.g. Ireland, Jersey). The Assisted Decision-Making (Capacity) Act 2015 in Ireland provides a modern statutory framework for supported decision making by adults who have difficulty in making decisions unaided. It repeals the Marriage of Lunatics Act 1811 and causes the Lunacy Regulation (Ireland) Act 1871 to cease to have effect. The Act provides for the replacement of the Wards of Court system for adults, which is the existing mechanism for managing the affairs of persons whose capacity is impaired, with a range of legal options on a continuum of intervention levels to support people in maximising their decision-making capability. The Act is intended to address three broad categories of people. These are people with disabilities, particularly intellectual disabilities, older people with degenerative cognitive conditions and people with mental health issues who may have fluctuating capacity. The philosophy of the Act is to safeguard the person's autonomy to the greatest extent possible, stressing the importance of the person's 'will and preferences'. To respond to the range of support needs that people may have, the Act provides for three types of decision-making supports, namely decision-making assistant, co-decision maker and decision-making representative:

- If a person considers that his/her capacity is in question or may shortly come into question, the person may appoint a:
  - Decision-making Assistant: to assist the person to access information or to understand, make or express decisions about his/her welfare, property

<sup>73</sup> Interdiction in Portugal and Romania.

<sup>74</sup> Curatorship in Lithuania and Incapacitation in Portugal and Romania.

<sup>75</sup> However, in some cases the judge may stipulate in the guardianship if the decision or act should be taken/done jointly by the guardian and the person under guardianship.

and/or affairs. However, decisions should be made by the person him/herself.

- Co-decision-maker: to assist the person to obtain the necessary information, explain the nature of the decision and establish the will and preferences of the person and to jointly make the decision(s) with the person regarding his/her welfare, property and/or affairs.
- For people who are not able to make decisions even with assistance, the Act provides for the Circuit Court to appoint a decision-making representative. This representative must, as far as possible, ascertain the will and preferences of the person. His/her functions should be as limited in scope and duration as is reasonably practicable.

The new Capacity and Self-Determination Law in Jersey was passed in September 2016. The new Capacity and Self-Determination Law (2016) will replace the system of curatorship (by the appointment of delegates in particular circumstances) and will introduce new protections, which are designed to ensure that people are enabled, so far as possible, to determine that their care and treatment are carried out in accordance with their own wishes. The purpose of this new Law is “to safeguard the dignity and wellbeing of people who may not have the capacity to make decisions for themselves, and enable them to make their own decisions wherever possible.” In cases where a person lacks the capacity to make a decision with support, the law provides a number of processes to ensure that the decision is made in that person’s best interests. The law applies to any decision affecting a person who may not have capacity, including decisions about how a person will be cared for and the medical treatment the person will receive, but also day-to-day decisions about how people live their lives and manage their finances.

### Ongoing reforms

In 2016, the Austrian Ministry of Justice presented a draft law for the legal protection of adults<sup>76</sup>. This new draft law includes 4 pillars for the legal protection of adults: enduring power of attorney (this measure already exists), opted representation (new measure), legal representation (expanded measure) and judicial representation of adults (used as a last resort and reviewed after 3 years).

In 2016, the Bulgarian government, issued a project of Law for Natural Persons and Measures for Support which looks at the topic of legal capacity and the conditions for providing support in carrying out specific legal actions. The

law gives a new arrangement of public relations related to the exercise of the rights of individuals who due to a number of reasons (intellectual disability, mental disorder or dementia) have difficulty in making decisions for specific legal actions. Whereas under current legislation, all cases result in the guardianship of the person (full or partial), the new law reinforces that such measures shall be determined only in cases of immediate risk to the life, health or property of the person. It also envisages the introduction of measures for supported decision making. However, this project of the law has still not been voted by the Bulgarian National Assembly and its result is still unpredictable.

In Portugal, Bill n° 61/XIII is currently being discussed at the Commission for Constitutional Affairs, Rights, Freedoms and Guarantees. This Bill includes some important changes in the Portuguese Civil Code and will modify the incapacity legal framework. Alzheimer Portugal was invited to contribute to this new Bill. According to the new Bill, the system of full incapacity will no longer exist in Portugal. The court order will expressly declare the acts or category of acts that the person is considered capable or incapable of doing, including the right to vote; the right to get married; the right to make a will; the right to donate; the right to live in cohabitation; the right to drive, etc. In addition, personal rights can be carried out by the person itself, with the guardian’s support, if needed. Another relevant change is that the Bill introduces the possibility of setting up organisations to represent or protect people under guardianship. The guardian will have to keep the person lacking capacity informed and respect his/her remaining autonomy.

The UK is also in a process of revisiting and re-thinking the existing legislation to better comply with the recommendations of the UN CRPD (Martin et al., 2016). In 2016, the Legislative Assembly in Northern Ireland passed the Mental Capacity Act. Also, the Scottish Government has recently completed a consultation about possible reform of the Adults with Incapacity (Scotland) Act; and recommendations to reform to the Mental Capacity Act are being prepared in England and Wales.

### 6.1.4 Principles of proportionality and subsidiarity

Recommendation N° R (99) 4 of the Council of Europe and the UN CRPD highlight the relevance of the principles of proportionality and subsidiarity in legal capacity. Several countries have reflected such principles in their legal systems, some examples include:

<sup>76</sup> Schyvens et al. 2016, presentation at 4<sup>th</sup> World Congress on Adult guardianship. Accessed online: <http://www.wcag2016.de/laenderberichte.html?&L=1>

- In Austria, a trustee should not be appointed if the person concerned could be assisted in a way which would be less intrusive or extreme, e.g. by a family member or a private or public institution. In 2006, the principle of subsidiarity was strengthened in the context of a comprehensive reform of sponsorship of alternative approaches towards more self-determination by the subjects of care. This means that the appointment of a guardian, with simultaneous loss of legal capacity of the subject, may now only happen if his/her specific needs cannot be met in any other way. It is a priority to select alternative approaches. The project, “Clearing Plus – support for Self-determination” was implemented in 2013. Among other tasks, guardianship organisations, can be asked by the Court to determine for a particular case, if an alternative to guardianship is possible. A member of the clearing staff ascertains the need for support and the person is involved in finding the alternatives to guardianship. In around one third of the cases examined in this project, it was decided that a guardianship measure was not necessary and other alternatives to guardianship were implemented.
- Similarly in Denmark, a guardian should only be appointed if the personal affairs of the person who lacks capacity cannot be satisfactorily managed in an informal way.
- In Germany, a guardian is only appointed for tasks for which guardianship is necessary. If the person’s affairs could be managed equally satisfactorily in a way other than by appointment of a legal representative, this should be done. Similarly, if a person merely needs help with household tasks or to leave the house, this should be arranged, without this necessitating the appointment of a legal representative.
- In the Netherlands, a cantonal judge may decide to establish a less intrusive alternative to full guardianship (i.e. mentorship), if the judge considers that this would be preferable for the person.
- In Finland, a person cannot be declared legally incompetent if the appointment of a guardian would be sufficient to protect his/her interests. If it is decided to restrict a person’s competence to act, the degree of restriction must not exceed that which is necessary to protect the person’s interests.

- In Malta, in determining whether or not a person is in need of a guardian, the Board must consider whether the needs of the person in respect of whom the application is made could be met by other means less restrictive of the person’s freedom of will and action.
- Similarly, in Croatia, the new Family Act stipulates, that deprivation of legal capacity should be a last resort, and the person’s needs, opinion, dignity and wellbeing should be considered (FRA, 2015).
- In Slovakia, a proposal for initiation of the proceedings has to contain a description of the evidence justifying the intervention into the individual’s legal capacity and a reason to justify, that a less restrictive action is not possible, or a description of the evidence justifying the change in the restriction of the individual’s capacity to legal acts, or evidence justifying the return of the individual’s capacity to legal acts (§ 234).

### 6.1.5 Who can ask for a guardian to be appointed?

When comparing the procedures set up by different European legislation in order to appoint a guardian for another person, one of the first differences can be found in the question of who can ask for a guardian to be appointed.

On the whole, the persons authorised to start the guardianship procedure are explicitly mentioned in the legal texts. The different actors that can be found in the legislation are the following:

- the person him/herself
- the person’s spouse
- another member of the person’s family or a close friend
- a representative of an administration (Local council, Police, etc.)
- a person involved in the care or treatment of the person for whom a guardian should be appointed (social worker, doctor, director of an institution, etc.)
- a legal representative (public prosecutor, judge, etc.)
- any person with an interest in the person’s welfare

Table 5 provides information by country on who can ask for a guardian (or supporter) to be appointed.

Table 5: Who can ask for a guardian or supporter to be appointed?

Country	Person him/herself	Family, friends	Administrative	Care/Medical	Legal	Anyone with an interest
Austria	X					X
Belgium	X		X <sup>77</sup>			X
Bulgaria		X			X	X
Croatia		X	X <sup>78</sup>			
Czech Republic	X	X	X	X	X	X
Denmark <sup>79</sup>	X	X	X			
Finland <sup>80</sup>	X	X	X			
France <sup>81</sup>	X	X			X	X
Germany	X	X		X		X
Greece	X	X			X	
Ireland						
Assisted/co-decision making	X					
Decision-making representative						X <sup>82</sup>
Italy	X	X <sup>83</sup>		X	X <sup>84</sup>	
Latvia		X		X		
Lithuania	X	X	X		X	
Luxembourg	X	X			X	
Malta <sup>85</sup>	X	X			X	X <sup>86</sup>
Monaco	X	X <sup>87</sup>			X <sup>88</sup>	
Netherlands	X	X <sup>89</sup>		X <sup>90</sup>	X	
Poland		X <sup>91</sup>			X	
Portugal		X <sup>92</sup>			X <sup>93</sup>	
Spain <sup>94</sup>	X	X		X <sup>95</sup>	X	X
Sweden	X	X <sup>96</sup>			X	
Switzerland <sup>97</sup>	X	X	X	X	X	X <sup>98</sup>
UK: England & Wales <sup>99</sup>		X				
UK: Scotland <sup>100</sup>		X				X

<sup>77</sup> The "procureur du Roi" can also apply for a guardianship order.

<sup>78</sup> Centre for social welfare.

<sup>79</sup> In Denmark, not only courts, but also regional authorities, are responsible for guardianship. The Public administration decides on guardianship unless it is considered inappropriate to handle the matter administratively or if the person objects, in which case, it is handed over to the court. The person concerned, his/ her spouse, children, parents, siblings or other close person, the guardian or special guardian, the local and regional council and the police director can ask for a guardian to be appointed.

<sup>80</sup> A guardianship authority (i.e. the local Registry Office), the person whose interests are to be looked after, as well as the guardian, parent, spouse, child or other person close to him/her.

As can be seen from the above table, the person him/herself and his/her family play an important role in almost all European countries when it comes to starting the procedure. Nevertheless, it seems important to underline that in some countries, the law does not specifically mention that a person can ask for a guardian to be appointed for him/herself and seems to leave that initiative to a third person.

### 6.1.6 The involvement of the person under guardianship and the right to be heard

Another relevant aspect relates to the right to be heard and express one's views, or if, in its absence, about the provisions for the person to be informed about the choice of guardian to be appointed. The right to be heard in this context can be described as "the expression of a person's will

and preferences related to the matters discussed in legal capacity proceedings" (Fallon-Kund and Bickenbach, 2016).

The legislation in some countries specifies that the person needs to be informed that such a procedure has been started. The judge may need to consult the person for whom a guardian is to be appointed in order to get a clear impression of the person's needs. If this is not possible in a court, the Judge should, in some countries, visit the person at home. Some examples of this can be found in Austria, Belgium, Denmark, Finland, France, Italy, Luxembourg, Monaco and Spain.

In several countries (Czech Republic, Germany, Latvia, the Netherlands, Spain, Sweden, Spain<sup>101</sup>, Switzerland and Turkey) the law further specifies that, the wishes of the person who lacks capacity, with regard to the person to be appointed as his/her guardian, should be respected as far as possible.

#### Box 5: Examples of respecting the wishes of the person

In Switzerland, if the person puts someone forward as his/her deputy, the adult protection authority shall agree to this person as deputy (provided the person is suitable and is prepared to accept the deputyship). The protection authority shall, if possible, consider the wishes of family members or other people who are close to the person. If the person rejects a specific person as his/her deputy, the adult protection authority shall respect this wish (provided it is reasonable).

In Sweden, the law specifies that the application for a custodian (god man), if possible, should be approved by the person who needs help for making decisions.

In Turkey, unless there are justified reasons, the court should appoint the person put forward by the individual whose capacity will be restricted.

<sup>81</sup> In France, the following people can initiate the process: the person who needs protection; the spouse, partner in a civil union contract or the common law spouse if the relationship is ongoing; any relative; anyone who has a close and stable relationship to the person; the person who exercises the legal protection; the state prosecutor in his/her own right or following a request from a third party (e.g. social services, health or medico-social centre etc.) and in certain cases, the judge.

<sup>82</sup> A relevant person, or any person who has attained the age of 18 years and who has a bona fide interest in the welfare of a relevant person.

<sup>83</sup> The spouse, or relatives up to 4th degree or relatives of the spouse to the 2nd degree.

<sup>84</sup> Health and welfare professionals who are aware of a situation for which appointment of a guardian is necessary are under the obligation to request the appointment of a guardian.

<sup>85</sup> The person, spouses, any person related to another who provides maintenance to the person, any person related by family ties and the Attorney General.

<sup>86</sup> This person should provide maintenance to the person who needs support to manage his/her affairs.

<sup>87</sup> The spouse, ascendants, descendants or siblings.

<sup>88</sup> The guardian, public prosecutor or the Court of First Instance.

<sup>89</sup> Spouse or partner, blood relatives in the direct line of descent, others up to and including the fourth degree.

<sup>90</sup> It can also be requested by the nursing home where the person lives.

<sup>91</sup> The spouse or a close relative.

<sup>92</sup> The spouse or by anyone in the family that can be an inheritor. Also the trustee (if someone was subjected to incapacitation, and the degree of the incompetence increases, the trustee can request the interdiction).

<sup>93</sup> The Public Attorney.

<sup>94</sup> Anyone can commence an incapacity proceeding by informing the Department of Public Prosecutions. Alternatively, the person with presumed incapacity, first and second degree relatives, the authorities or public officers must inform the Department of Public Prosecutions if they are aware of any grounds for incompetence.

<sup>95</sup> A social worker for example.

<sup>96</sup> Immediate family.

<sup>97</sup> The deputyship shall be established at the request of the person concerned or a closely associated person or ex officio.

<sup>98</sup> This is possible in Switzerland, but often not sufficient.

<sup>99</sup> A person who is 18 or over. Deputies are usually close relatives or friends of the person who needs help making decisions.

<sup>100</sup> Anyone with an interest in the adult can apply to the sheriff court for an order. The local authorities have a statutory duty under the Adults with Incapacity (Scotland) Act to apply for welfare guardian for an adult who lacks decision-making capacity and there is no other existing welfare attorney or anyone able or willing to apply to be a welfare guardian.

<sup>101</sup> In Spain, the person can decide in advance who he/she will be his/her tutor in the event of incapacity ("autotutela").

In contrast to the above-mentioned examples, the legislation in Bulgaria, Malta, Portugal and the UK contains few or no provisions for a direct involvement of the person for whom a guardian is to be appointed in the process of making decisions. Some countries have provisions about the involvement of a close relative in the proceeding, but not about the person him/herself. For example, in Greece, the spouse of the person who is to be incapacitated as well as the person making the request, attend the Court in order to provide information on the person but they cannot take part in the decision-making process or give their opinion.

### 6.1.7 Who appoints a guardian?

It is interesting to note that in the majority of the countries, a guardianship decision is taken by a judge after court proceedings. Some exceptions include:

In Denmark, the law allows for an administration (i.e. the Council) to appoint a guardian, unless:

- the person for whom a guardian is to be appointed objects
- the person's right to conduct business would be affected by a guardianship decision
- it is considered to be otherwise inappropriate for the Council to take such a decision

In Finland, whilst the appointment of a guardian is usually made by the District Court, in some cases, the local Registry Office may appoint a guardian if the person seeking a guardianship order can still make some decisions. In such cases, the person for whom a guardianship will be appointed must be able to understand the meaning of the issue and to express his/her wish about who he/she wants to be appointed as his/her guardian.

In Switzerland, the Adult Protection Authority ("Erwachsenenschutzbehörde") appoints the guardian. The members of this authority should represent several professions: psychologists, social workers, jurists, etc.

### 6.1.8 Who can be appointed as guardian?

As with the decision of who can start a guardianship procedure, there are a number of possible guardians to be appointed. They can be:

- a member of the family of the person who needs support for making decisions

- a person in charge of the person's care, in some cases for example a social worker
- a specialised lawyer, solicitor or accountant
- organisations specialised in dealing with guardianship measures
- any other person deemed fit by the judge

When looking at the existing legislation, there seems to be a division of countries, in particular with regard to the role of the family in an eventual guardianship.

Some laws specifically give a preference to a family member or person close to him/her<sup>102</sup> (e.g. Belgium, Bulgaria, Czech Republic, France, Greece, Italy, Luxembourg, Malta, Monaco, Netherlands, Poland, Portugal, Spain, Slovakia and the UK). In these cases, the appointed guardian is normally the spouse of the person under guardianship, his/her adult children or another close family member or friend. In the absence of an adequate person in the family of the person, another person can normally be appointed as a guardian. Typically, in this case, it is up to the judge's discretion to appoint a guardian he/she considers qualified<sup>103</sup>. Similarly, in Ireland, the Act explicitly states the relevance of the existence of "a relation of trust" between the person and the co-decision-maker.

In some countries the law provides that more than one guardian can be appointed, if necessary<sup>104</sup>. In Bulgaria, for full guardianships a "legal guardianship council" (composed of a full legal guardian, a deputy full legal guardian and two advisors from the family and close friends of the person under guardianship) should be appointed. For trusteeship, a trustee and a deputy trustee from among the relatives and close friends are appointed (trusteeship council). In a similar vein, in Greece, all acts of the legal representative are under the supervision of a board composed of three to five family members or/and friends of the person under guardianship. In Luxembourg, a family council can be appointed in the case of assets that are particularly large or if there are serious problems between family members.

The laws in Austria, Denmark, Finland, Germany, Lithuania and Sweden have taken a slightly different approach since in these countries there is a greater emphasis on the qualifications and skills of the guardian rather than on his/her relationship with the person under guardianship. However, in practice, the information reported by the different countries participating in this report, suggests that in these countries the guardian is nevertheless quite often someone who has a close relationship with the person (e.g. the spouse or next of kin).

<sup>102</sup> Still, in most cases it is also specified that the appointed person should be able to perform his/her functions or duties as guardian (or as co-decision maker in the case of Ireland).

<sup>103</sup> Unless as explained in previous section the person who needs help for decision making him/herself puts forward a person, in such cases, his/her wishes should be respected.

<sup>104</sup> To take care of different matters or as in the case of Finland, to take care jointly of the duties.

## Box 6: Example from Finland and Lithuania

In Finland, guardians must fulfil certain criteria. They must be legally competent, suitable for the post and have consented to appointment. In assessing suitability, the court or guardianship authority bases its opinion on the ability and experience of the prospective guardian, as well as the nature and scope of the task. If necessary, several trustees can be appointed and the duties divided between them.

In Lithuania, the moral qualities of the person, capacity to perform the function of guardian or curator as well as the preferences of the ward must all be taken into account when deciding the person that should be appointed.

In some countries (Austria, Czech Republic, Ireland, Monaco) the law stipulates that the owner (or an employee) of the centre or facility where the person resides, or in the case of the Austria and the Czech Republic, any other service provider, or a General Practitioner in Monaco and Luxembourg, cannot be appointed as guardians<sup>105</sup>.

### 6.1.9 Powers of a guardian: scope and limits of the guardian's authority

The duties and responsibilities of guardians are summarised in Appendix 2.

In terms of scope, the court can grant the guardian the legal right to make decisions for welfare and/or financial affairs. Whilst in the past, it was not unusual that guardianship measures only covered financial affairs, the reforms in legislation have substantially changed this. For example in Belgium, since the reform introduced by the law in 2014, an “administrator” can be appointed and given powers of proxy decision making in relation to a person's finances and properties and/or in relation to the exercise of certain individual rights, such as choice of place of residence, exercise of patient's rights, etc. This differs from the previous regime in Belgium under which only decisions for the person's property and financial affairs could be conferred. Similarly in France, the legislation introduced in 2007 helped to clarify the role of legal guardians, and also introduced the possibility of the guardians providing social support in addition to financial issues. Still in a few countries, there is a greater emphasis on financial issues, this is the case for example in Cyprus, Luxembourg and Monaco.

In some countries, provisions exist so that certain decisions can never be made on behalf of someone, these are typically referred to as “strictly personal decisions/issues”. These are acts which cannot be accomplished by anyone else than the person concerned. Austria, Belgium, Croatia, the Czech Republic, Finland, France, Ireland, Spain and the UK have provisions for this (see Appendix 2 for further details).

- In Austria, Belgium and the Czech Republic<sup>106</sup>, a guardian cannot make decisions regarding the place of residence of the person or the right to bodily integrity.
- In Belgium, Croatia, Finland and Spain a guardian cannot consent for marriage on behalf of the person, adoption, or any other issues of an equally personal nature. In the UK (England and Wales) some types of decisions (such as marriage or civil partnership, divorce, sexual relationships, adoption and voting) can never be made by another person on behalf of a person who lacks capacity.
- In Denmark and Italy, the person retains capacity for everyday life decisions.

### 6.1.10 Involvement of the person in decision making

A number of countries have provisions in their law which state the involvement of the person in decision making. In Austria, for example, the law stipulates that the trustee should be in contact with the person at least once a month. In several countries, it is stipulated that the person has to be informed about and his/her opinion on the matter sought. This, however is often only necessary in the case of “important” decisions. An interesting case is Turkey, where whilst the person can be asked, the expressed opinion is “not binding”. In most of the other cases, the guardian should respect the person's preferences and wishes. However, both the need to consult the person and the need to respect his/her preferences are only applicable if the person is considered to have capacity to do so, and/or if the expressed wish is considered as “appropriate” or does not conflict with the person's welfare. Please see Table 6 for further details regarding this matter.

In the case of a curatorship (like in France, Luxembourg and Spain for example), generally the curator is not expected to make any decisions on behalf of the person, rather the role is to advise, support or help the person in making the decision. Also, in some cases the guardianship order has to

<sup>105</sup> Decision-making assistant in the case of Ireland.

<sup>106</sup> For the Czech Republic this applies only if a guardianship council has been set.

specify if the decision has to be made jointly with the person and guardian or by the guardian on behalf of the person.

In Ireland, the legislation is based on mechanisms that ascertain the need of support and the level of support that the person may need for making a decision. Three different levels exist: decision-making assistant, co-decision maker and decision-making representative. Only in the last case, the supporter may need to make decisions on behalf of the person. In Jersey, the new law makes provisions for the appointment of independent capacity support workers, to provide assistance and support to persons lacking capacity to make certain decisions, and to support the person to participate as fully as possible in any decision concerning him/her.

A particular difficult situation relates to people who cannot participate, even with support, in the decision-making process. This is particularly relevant in the case of severe stages of dementia where the person's communication usually becomes more impaired. Discussions exist as to how this should be considered and, for a long time, the "person's best interest" has been considered the main principle in which decision making on behalf of others should be made and this is reflected in many laws (e.g. England and Wales<sup>107</sup>, Northern Ireland, Jersey, Malta etc.). In these cases, the best interest of the person is the main principle and within it, the will and preference of the person are mentioned and have to be taken into account.

In Scotland, the Act avoids any mention of "best interests", and requires three general principles (i.e. benefit, least restrictive option and wishes of the adult), none of which is stated to take precedence or priority over any other, to be applied when deciding which measure will be most suitable for a person.

Following the UN CRPD requirements which stress the relevance of the "best interpretation of a person's will and preferences", some legislative frameworks (e.g. Ireland) have shifted the emphasis on best interest to the person's past and present will and preferences. In a position paper, the Alzheimer Society of Ireland stated that this shift will help to focus decision making on the guiding principles of autonomy, dignity, privacy and bodily integrity. They believe that whilst "to date, decisions have been made for people, presumed to be lacking capacity, in their best interests regardless of whether a person or family member claims an alternative decision or had previously expressed an alternative preference to what is perceived as in their best interests. The legislation will place an onus on those requiring a decision to be made to ensure that a person is involved in that decision, capacity is assumed and a decision is based on a person's values, wishes and will and preferences" (Alzheimer Society of Ireland, 2016:8).

In Ireland, Jersey and Northern Ireland, special regard is also given to the beliefs, values or any other factors that the person would be likely to consider or that would have been likely to influence the person's decision if the person had capacity.

<sup>107</sup> A recent report (2014) on the MCA recommended the amendment of the best interests standard in the act through the adoption of the "rebuttable presumption approach". On such an approach, "a best-interests decision-maker must start from the presumption that, when a decision must be made on behalf of a person lacking in mental capacity, and the wishes of that person can reasonably be ascertained, the best-interests decision maker shall make the decision that accords with those wishes". (...) "The Law Commission of England and Wales has provisionally proposed that the MCA should be amended to establish that decision makers should begin with the assumption that the person's past and present wishes should be determinative of the best interests decision" (Martin et al., 2016:8 and 20).

Table 6: Examples of involvement of the person lacking capacity

Country	EXAMPLES OF INVOLVEMENT OF THE PERSON IN DECISION MAKING
Austria	The trustee should be in contact with the person at least once a month <sup>108</sup> . The trustee must inform the person of any important decisions and must give the person sufficient time and opportunity to express his/her views. The views must be taken into consideration (provided that the wish expressed is appropriate).
Czech Republic	The guardian usually acts jointly with the person; if the guardian acts individually, the guardian shall act in accordance with the will of the person. If the will of the person cannot be ascertained, the decision should be made by a court on the application of the guardian.
Denmark	The guardian cannot make or enforce a decision if the person is opposed. The guardian must try to involve the person when making important decisions however this obligation only applies if the person is able to understand.
Finland	The wishes of the person should be taken into account when making decisions. Before making a decision that is of importance to the person, the guardian must ask the person's opinion on the matter.
Germany	The wishes and ideas of the person have to be taken into account. The guardian has to comply with the wishes of the person (as long as wishes do not conflict with the person's welfare) The guardian should discuss any important decisions with the person beforehand.
Ireland	As a principle when making (or supporting) a decision, the participation of the person should be permitted, encouraged, improved and facilitated as much as possible. The past and present will and preferences of the person (in so far as that they are reasonably ascertainable), the beliefs and values of the person (in particular those expressed in writing), and any other factors which the person would have been likely to consider, should be also taken into account.
Jersey	The past and present wishes and feelings of the person as well as the beliefs and values of that person which would be likely to influence that person's decision if that person did not lack capacity, should be considered. The independent capacity support workers, should support the person to participate as fully as possible in any decision concerning him/ her.
Malta	The will of the person is respected and given effect to the maximum extent possible. The guardian should consult the person and take into account and respect his/her rights, will and preferences. The guardian shall support the person in exercising his/her legal capacity him/herself (if this is possible) and encourage the person to participate as far as possible in the life of the community and to become capable of caring for himself and for his property and of making responsible judgements in respect of matters relating to his person and property.
Monaco	In curatorship, the person should be involved in all decisions.
Netherlands	The guardian must try to involve the person as much as possible in the performance of his/her duties. This means encouraging him/her to enter into legal and other dealings, provided that he/she is in a fit state to make a reasonable assessment of his/her interests in the matter.
Poland	Before making any important decision the guardian should listen to the person and take his/her wishes into account (if the person's health and mental condition allows).
Switzerland	The deputy shall carry out his/ her tasks in the interests of the client, take account the person's opinions, where possible, and respect the person's desire to organise his/ her life in a way that corresponds to his/her abilities, wishes and ideas.

<sup>108</sup> This does not apply if the trustee is only entrusted with single affairs.

Country	EXAMPLES OF INVOLVEMENT OF THE PERSON IN DECISION MAKING
Turkey	The guardians are exceptionally required to ask the person for his/her unbinding opinion when he/she has power of judgement or is able to otherwise form an opinion and express it.
UK: England	Deputies must consider someone's level of mental capacity every time a decision for them is made. It cannot be assumed that capacity is the same at all times and for all kinds of things. When making a decision, the deputy must: <ul style="list-style-type: none"> <li>• make sure it is in the person's best interests</li> <li>• consider what the person has done in the past</li> <li>• apply a high standard of care</li> <li>• do everything to help the person understand the decision</li> </ul>
UK: NI	When an act is done or a decision is made on behalf of a person who lacks capacity, the act must be done, or the decision must be made, in the person's best interests. Special regard should be given to the person's past and present wishes and feelings (in particular, any relevant written statement made by the person when he/she still had capacity); the beliefs and values that would be likely to influence his/her decision and other factors that the person would be likely to consider if able to do so. The person making the decision or acting on behalf of the person should consult and take into the account the views of the relevant people about what would be in the person's best interests.
UK: Scotland	Any guardian, continuing attorney, welfare attorney or manager of an establishment exercising functions under the Adults With Incapacity Act must take account of the general principles of the Adults With Incapacity Act. There are five general principles: <ul style="list-style-type: none"> <li>• Principle 1: Any action or decision taken must benefit the person and only be taken when that benefit cannot reasonably be achieved without it.</li> <li>• Principle 2: Any action or decision taken should be the minimum necessary to achieve the purpose. It should be the option that restricts the person's freedom as little as possible.</li> <li>• Principle 3: In deciding if an action or decision is to be made, and what that should be, account must be taken of the present and past wishes and feelings of the person, as far as these may be ascertained.</li> <li>• Principle 4: Take account of the views of others with an interest in the person's welfare. This includes the person's primary carer, nearest relative, named person, attorney or guardian (if there is one).</li> <li>• Principle 5: encourage the person to use existing skills and develop new skills.</li> </ul>

### 6.1.11 Safeguards and protection of people under guardianship from misuse of power

The appointment of a guardian is an important step as this guardian can take decisions in important aspects of the life of the person. It seems therefore important to ensure the protection of this person against a possible misuse of the powers of the guardian. The national legislation in the participating countries foresees different safeguard provisions that can protect the person against misuse of power.

the Court or other Authority (e.g. Public Administration in Denmark). Such is the case with respect to decisions relating to change of residence of the person, deprivation of liberty and for decisions relating to the management of the finances or property of the adult beyond the usual affairs (for example buying or selling property, withdrawing a large amount of money from the account, making gifts, etc.).

In several cases, the guardian is limited in the acts or decisions that he/she can take<sup>109</sup>. Also, some laws list a number of situations where a guardian requires prior approval from

Some countries have provisions in the case of a conflict of interests between the guardian and the person under guardianship, some examples include:

<sup>109</sup> By law or as stated in the court order.

- In Belgium, if there is a conflict of interest for a particular issue the guardian must obtain a special authorisation from the Justice of Peace.
- In the Czech Republic, Denmark and Spain, if there is a conflict of interests between the guardian and the person, a guardian “ad litem”<sup>110</sup> is appointed by Court<sup>111</sup>, in the case of the Czech Republic, and by the Public Administration, in Denmark.

In some countries (Belgium, Finland, Malta, Poland, Romania, Switzerland and Scotland) the guardian must submit an inventory of the assets and properties of the person quite shortly after he/she has been appointed. In Scotland<sup>112</sup> and Finland<sup>113</sup>, guardians may be required to submit a management plan. The laws of the different countries envisage a system whereby guardians must submit regular reports of their financial dealings on behalf of the person (typically on an annual basis and at the end of guardianship). Specific provisions in this respect exist in Austria, Belgium, Bulgaria, Cyprus, Denmark, Finland, France, Germany, Italy, Luxembourg<sup>114</sup>, Malta, Monaco, the Netherlands<sup>115</sup>, Portugal, Romania, Spain, Sweden, Switzerland and the UK.

Interestingly, only in a handful of countries, guardians have to report regularly on different aspects of the person’s welfare to the Court. This is the case of Austria, Germany, Italy, the Netherlands<sup>116</sup>, Poland, Spain, Switzerland and the UK, where, in addition to the financial report, the guardian must report on the welfare of the person to the court. This include details of the contact the guardian has had with the person, and the living and housing situation of the person. In Germany, it should also include information on the health status of the person under guardianship and whether the guardianship may need to be reduced or extended. In Austria, it is the duty of the Court to verify at appropriate intervals if the guardianship is still needed and if the current arrangements address all the needs of the person. In the UK (England and Wales), the deputy should write a report explaining, for every decision that he/she has made as a deputy, the reasons for the decision, why they were in the person’s best interest and who else the deputy spoke to when making the decision. In Scotland, welfare guardians are supervised by the local authority in the area where the person lives. The responsibility usually falls to the local social work department.

### Box 7: Example of safeguards (UK, England and Wales)

The Office of the Public Guardian (England and Wales) has recently introduced new deputy report forms. The new forms are tailored to their deputyship order. The forms include additional questions and a new safeguarding section. Deputies are asked, for example, to detail the level of contact they have with their client, how the client’s care is funded and whether the client is receiving all their entitled benefits. These areas are regarded as early indicators that a client may be at risk of neglect or a red flag that the client is not receiving adequate support. Deputies also need to provide information on the client’s care arrangements, and health and social activities. This is to identify whether the client is receiving the appropriate level of support.

*Office of the Public Guardian, online information<sup>117</sup>*

In the majority of the countries, guardianships are established for an unspecified period of time or for as long as the condition for which a guardian was appointed exists (Austria, Belgium, Bulgaria, Denmark, Greece, Lithuania,

Monaco, Poland, Portugal, Romania, Sweden, Switzerland and the UK). On the other hand, in some countries, guardianship measures are restricted to a limited period after which the initial decision has to be reviewed (Czech

<sup>110</sup> Ad litem is Latin for ‘for this action’.

<sup>111</sup> “Defensor judicial” in the case of Spain.

<sup>112</sup> In the case of Scotland, the plan covers specific information about the adult’s day to day needs e.g. utilities, mortgage, rent, care costs, hobbies and holidays. It can also include the guardian’s suggestions for the management of the adult’s property and/or finances in the long-term. The guardian needs to take financial advice as how best to manage the adult’s property and finances if they have more than of £25,000 of moveable assets e.g. bank/building society accounts.

<sup>113</sup> In Finland, in the case of large assets, the guardian may be required to establish a plan for the management and use of assets.

<sup>114</sup> For a curator with responsibility for collecting and investing revenue.

<sup>115</sup> In the Netherlands, the report of the accounts should be submitted to the person under administration, this should be done in the presence of the cantonal judge.

<sup>116</sup> In the case of mentorship.

<sup>117</sup> <https://www.gov.uk/government/news/new-deputy-report-forms-to-improve-safeguards-for-at-risk-adults>.

<sup>118</sup> Three years.

<sup>119</sup> Tutorship and curatorship should not exceed five years, but under certain circumstances it can be extended to ten in the case of tutorship and 20 for curatorship.

<sup>120</sup> No longer than seven years.

<sup>121</sup> The review of the order shall be held within a specified period, not being longer than two years

<sup>122</sup> Two years.

Republic<sup>118</sup>, France<sup>119</sup>, Germany<sup>120</sup>, Luxembourg, Malta<sup>121</sup> and Turkey<sup>122</sup>). In Finland, the guardian can be appointed for a fixed or indefinite period of time. In Italy, Luxembourg and in the Netherlands, if the guardian is a spouse or a relative, the guardian can be appointed for an unspecified period of time, however in any other case, guardianships are limited to five years in Luxembourg, eight years in the Netherlands and ten in Italy.

It is the responsibility of the court (or the guardianship authority or board) to oversee and monitor guardianship cases<sup>123</sup> (Austria, Finland, Lithuania, Malta, Netherlands, Slovakia, Turkey and the UK<sup>124</sup>). In some countries, the guardian can receive a visit (for example, in the case of England by a court of protection visitor) or may be asked to attend a hearing and

provide information at any stage of the guardianship. Another system of protection put into place by national legislation is the appointment of a special control organ of the Ministry of Justice or Court supervising the activities of guardian organisations as in Austria<sup>125</sup>, Sweden<sup>126</sup> and Switzerland.

The court has the power to modify, revoke or terminate the guardianship if the guardian fails to fulfil his/her duties. In some countries, if the guardian causes damage or loss as a result of negligence, the guardian is liable and can be required to compensate the person (Denmark, Germany, Lithuania and Turkey). In some countries, the legal system foresees that the guardian can be fined, or even sent to prison in the case of abuse or neglect (Finland, Poland and the UK).

### Box 8: Example of safeguards (UK, Scotland)

It is an offence for anyone exercising welfare powers under the Act to ill-treat or neglect an adult. The penalties for someone found guilty on summary conviction of the offence under the Act are up to 6 months imprisonment or a fine of up to £5,000. Someone convicted of the offence on indictment may be imprisoned for up to 2 years or given an unlimited fine.

*Code of practice for persons authorised under intervention orders and guardians*

## 6.2 Anticipated measures set up by the affected individual: power of attorney

Many countries have in place alternatives to guardianship. Most often these alternatives require prior planning, which should be done well before the individual's capacity becomes an issue. The section on consent to medical treatment and research has already provided an overview of some such alternatives when it refers to welfare or health-related decisions (e.g. advance directives, health care proxies). This section provides information on another alternative that could address welfare and also financial affairs: power of attorney.

### 6.2.1 Power of Attorney

A power of attorney (PoA) is an authority given by an individual (the grantor, donor or principal) to another person(s) (the attorney/s or agent) to deal with aspects of the grantor's affairs. This could relate to financial matters and in some countries, personal welfare<sup>127</sup>. One or more attorneys can be appointed. A special type of power of attorney is the lasting, durable or enduring power of attorney which can be used beyond the disability of the donor<sup>128</sup>.

<sup>123</sup> In some cases other bodies are also involved, in Scotland for example the Public Guardian supervises any guardian in the exercise of his/her functions relating to the property or financial affairs of the adult, local authorities have a major role in looking after the welfare of adults with impaired capacity and the Mental Welfare Commission has a role in protecting the interests of adults whose incapacity is the result of mental disorder.

<sup>124</sup> The Public Guardian.

<sup>125</sup> Only for cases where there is an organisation acting as a trustee.

<sup>126</sup> Single public trustee or a committee of public trustees.

<sup>127</sup> In Malta, a general power of attorney enables the agent to act in the name of the grantor for any type of action, a special power of attorney enables the agent to conduct one or more actions of certain type on behalf of the donor.

<sup>128</sup> Greece and Monaco reported that there are no legal provisions in their country concerning lasting powers of attorney.

<sup>129</sup> In England and Wales, it is possible to make an LPA online, still it will need to be registered.

<sup>130</sup> This only applies to PoA for financial or property affairs. Usually, welfare powers cannot be exercised until the grantor has lost the capacity to make these decisions.

<sup>131</sup> In Switzerland, the "Vorsorgeauftrag" (advanced disposition) comes into force only when the "client" has lost his capacity. But not automatically only by a disposition of the authority of protection of adults.

A main difference between PoA and guardianship, is that a PoA is drawn up by the person, when he/she has the mental capacity to do so. Also, with a PoA, the person gives the power to make decisions on his/her behalf to an attorney of his/her choice. This allows the person to have more control:

- over whom he/she wishes to help him/her make decisions or to make decisions on his/her behalf and
- about the decisions that person is allowed to make

Typically, for a PoA to be valid it has to be in writing, dated and signed by the person, registered<sup>129</sup>, and often it has to be signed in the presence of a notary or witnesses.

In some countries, a power of attorney<sup>130</sup> can have effect immediately after it has been registered and can continue upon the donor's incapacity (Belgium, Finland, Italy, Switzerland<sup>131</sup> and the UK). In these cases, the PoA can have a clause ("springing clause") where it is specified if the powers will take effect immediately and continue upon the donor's incapacity, or will only begin on his/her incapacity. In Switzerland, for the powers to be continued to be exercised after the person has lost capacity, it has to be explicitly stated in the document. In Scotland, it is recommended that if the PoA is to begin only in the event of incapacity, the document should include a statement confirming that the donor has considered how their incapacity is to be determined. In England and Wales, the "attorney" can start helping the donor make decisions about property and finances immediately if the person gives permission. If the person does not give permission, the attorney can only make a decision when the donor lacks the capacity to make it. In the case of health and welfare PoA, it is only possible to make decisions once the donor does not have the capacity to make it.

In Austria, France<sup>132</sup>, Jersey<sup>133</sup>, Germany and Ireland<sup>134</sup> the powers can only be exercised once the donor has lost capacity to make decisions. However, in France, unless the Judge decided otherwise, a PoA cannot coexist with a guardianship order<sup>135</sup>.

In Belgium and Italy, if a person has lost capacity it has to be determined by the Judge if the PoA is compatible with a

guardianship. If so, in Belgium, the Justice of Peace should also determine the conditions under which it can continue to be exercised. In Bulgaria, the PoA automatically becomes invalid if a person is placed under full guardianship. In Italy, the PoA is only valid until the "amministrazione di sostegno" has been implemented.

In terms of its scope, in some countries, a PoA is used mainly for the administration of a person's assets or patrimonial affairs (Belgium, France, Finland, Germany and Slovakia). However, in some countries, it can also include matters concerning the person's welfare or other personal matters (Austria, Ireland, Jersey<sup>136</sup>, Malta<sup>137</sup>, Portugal, Switzerland and the UK).

In Austria, in addition to PoA, it is possible to grant agent's authority to a next of kin (Vertretungsbefugnis nächster Angehöriger) if guardianship is not necessary but due to mental illness or disability, the person is unable to manage his/her legal affairs or personal matters. However, it is only possible to grant such authority to a next of kin if the person does not already have a trustee and has not already granted a durable power of attorney for legal representation (Vorsorgevollmacht). To obtain an agent's authority, a person must submit a medical certificate in which it is stated that the person concerned lacks legal capacity, submit it to a public notary along with proof that he/she is the next of kin. This is then entered into the Central Austrian Register of Representation. Eligible next of kin include parents, children and spouses (or unmarried partners who have lived together for at least three years).

In Switzerland, any person who as spouse or registered partner cohabits with a person who is no longer capable of judgement or who regularly and personally provides that person with support has a statutory right to act as that person's representative if there is no advance care directive and no deputy has been appointed. The right to act as representative includes: all legal acts that are normally required to meet the need for support; management of income and other assets; and the right to open and deal with post, if necessary. For legal acts involving exceptional asset management, the spouse or the registered partner must obtain the consent of the adult protection authority.

<sup>132</sup> Mandate for future protection.

<sup>133</sup> The new law that has been passed in September 2016 would permit the creation of lasting powers of attorney.

<sup>134</sup> This was introduced with the New Act.

<sup>135</sup> Tutorship or curatorship.

<sup>136</sup> In Jersey, health and welfare LPAs do not override any advance decision to refuse treatment, and property and affairs LPAs do not confer, except to the extent stipulated, any right to dispose of the property of the person who has conferred the authority, by making gifts (explanatory note to the draft Capacity and self-determination (Jersey) Law 201).

<sup>137</sup> In Malta, a durable power of attorney gives the donor the possibility to have his/her business or personal matters easily covered after becoming incapacitated. Through the durable power of attorney, a donor can grant general or limited power.

## 6.3 Personal account



### Helen Rochford-Brennan, member of the EWGPWD

In the early days of my diagnosis, I jokingly said ‘I’m not ready to give up my credit card just yet’. I said this because we know too often that a dementia diagnosis can mean a person is denied basic rights like the right to manage their own finance or the freedom to travel.

Too often, a fluctuating or decreasing capacity to make decisions is used to deny a person these fundamental rights. But we also know that with the adequate supports, people living with dementia can continue to participate in decisions that impact on our lives either directly or through

a trusted loved one or significant other in our lives.

As a person living with dementia, the passing of the Assisted Decision-Making Act in Ireland means that I am no longer subjected to the archaic 1871 Lunacy Act. The Assisted Decision-Making Act, if implemented on the ground through practice and services, will have a profound impact on my life. It will mean that my voice is heard in decisions that shape my quality of life and my future. It will also mean that my family and loved ones now have a statutory framework to speak out for me and uphold my wishes if I no longer can.

The functional approach to capacity in the Act, recognises that there are times when a person’s capacity to make decisions can fluctuate. For people with dementia, this is an important new development in the Irish approach to assessing capacity. In addition, instead of decisions being made in my best interests, the focus on will and preferences in the Act acknowledges my interests, and needs, before and during my journey with dementia. In this way, the Act ensures that a lack of capacity to communicate or articulate a decision does not take away my inner voice or personhood. Fundamentally, the Act will force a cultural shift in the health and social care system. In time, I hope to see a decrease in the use of chemical restraint and a decrease in the number of people admitted to institutional care against their wishes. For me and the 55,000 other people living with dementia in Ireland, I am delighted that this legislation has been passed and I look forward to the Irish Government ratifying the Convention on the Rights of People with Disabilities.





## 7. Conclusions

Dementia affects around 9 million people in Europe. Dementia is a progressive condition, which means that the symptoms will gradually worsen. It often involves a decline in memory, communication and reasoning skills, as well as difficulties carrying out daily activities. The rights of people with dementia need to be respected and reinforced in situations where the person may need support or may lack the capacity to make decisions. Respect for fundamental rights, such as the right to self-determination, the freedom of the individual and the integrity of the human body, should remain paramount and dictate the approach taken to find and implement legal solutions to the problems faced by people with dementia and their families.

This report has looked at the topic of decision making and legal capacity for people living with dementia. Alzheimer Europe has reviewed this topic over the last two decades and has published a number of reports and recommendations on how to improve the legal rights and protection of adults with dementia and a position paper on advance directives. We realise that the field has changed quite significantly and that many countries in Europe are working to incorporate the recommendations of International Conventions, of the Council of Europe and the United Nations, into their legislative frameworks.

A core principle is the assumption in favour of capacity, involvement and choice. Every individual should have the right to decide how he/she wants to lead his/her life and his/her autonomy should be respected at all times. Other principles such as beneficence, justice and non-maleficence should also be borne in mind and balanced with respect for the person's right to self-determination. For as long as it is possible, people with dementia should be offered the opportunity to make decisions about their health and care, and about their participation in research. This report shows evidence of an increasing amount of legislation on patients' rights and provisions about involvement of patients in Europe, in particular insofar as this relates to informed consent.

In the context of health care, promoting the autonomy of people with dementia means allowing and enabling them to make their own decisions about their health care and research participation. Most countries have legislation aiming to protect the autonomy of the person and to ensure that informed consent is provided for medical interventions. Another way of promoting autonomy, is allowing the person

to make decisions on who should decide on his/her behalf at the time he/she is no longer able to do so, and to write advance directives with regard to the treatment and care that the person would like to receive.

Advance directives and lasting powers of attorney can constitute a real opportunity for people with dementia to exercise their right to self-determination with regard to the management of their condition and lives. Most forms of dementia involve the gradual and irreversible deterioration of cognitive abilities (memory, language and thinking etc.). However, many people with dementia can make decisions concerning their finances, personal welfare, medical treatment and possible participation in research. This underlines the importance of timely diagnosis, disclosure of the diagnosis to the person with dementia and provision of information about the implications of the diagnosis and the prognosis. It is important to inform people about the existing mechanisms (health care proxy, lasting power of attorney, advance directive etc.) whilst they still have the necessary capacity to write one, should they eventually decide to do so. Later on in the illness, forward planning becomes more difficult because of the progressive impairment, which is central to dementia.

However, it is important to bear in mind that some countries in Europe have not adopted a legal framework for advance directives. Also, in the countries where provisions exist, the scope of these documents is often limited and in many cases only related to very specific conditions (e.g. end-of-life care). The relevance of informing people with dementia and their families about such mechanisms was highlighted in our previous work, and should again be stressed in this report. Also, in line with Resolution 1859 (2012) and Recommendation 1993 (2012) of the Parliamentary Assembly of the Council of Europe, countries where these mechanisms are legislated should ensure that the relevant Council of Europe standards are met, and that the general public, as well as the medical and legal professions, are sufficiently aware of it and implement them in practice.

The report has also emphasised how several countries in Europe have, in the last two decades, significantly modernised their legislation and the legal responses that could be offered to a person who may experience difficulties or need help for making decisions or in exercising his/her legal rights. In particular, international recommendations

underscore the following principles: the principle of presumption of capacity, the principle of proportionality and necessity, and the respect of the will and preferences of the person. All adults should be presumed to have decision-making capacity and therefore be afforded the right to self-determination (i.e. the freedom to make decisions for themselves in all areas of their lives). However, for people with disabilities, including people living with dementia, this has not always been the case. The assumption of legal capacity in the legislation is particularly relevant as it takes the focus away from the impairments towards putting into place appropriate supports that could enable the person with dementia to make decisions for him/herself. Accordingly, many countries nowadays seem to have incorporated a functional approach to their assessment of capacity. In this approach, the definition of capacity is related to specific decisions at a specific point in time, and the question no longer be phrased as “Is this person competent?” but as “Is the person competent to do X in Y context?”.

An individual with dementia should be given all the help and support he/she needs before anyone concludes that the person cannot act in his/her own interests or make his/her own decisions. This also implies recognising which decisions the person can make and which they cannot make. For example, a person may be able to make some simple decisions, but not others. In the report, we have provided examples of how this has been incorporated in the capacity legislation in Ireland, Jersey and the UK.

Major changes also include the reforms that have taken place in several countries to eradicate or modernise the systems of plenary guardianships and promote guardianship measures that are more flexible and adapted to the person's level of capacity. This has resulted in a range of guardianship measures that could correspond better to the increasing lack of legal capacity of the person for whom a guardian should be appointed. Most countries have systems whereby a judge has a certain latitude when pronouncing a guardianship measure. These systems allow the judge to specifically include or exclude certain decisions from a guardian's remit and to allow the adult to take certain

decisions him/herself despite the guardianship, so that the judge can opt for a system best suited to the needs of the person for whom a guardian needs to be appointed. It would appear, that in most countries, restrictive forms of guardianship should only be used as a last resort and that when used, appropriate safeguards should be in place to protect the person. The report did not cover aspects related to the implementation of these measures, but there is information elsewhere indicating that countries which have modernised their legal systems, have experienced a decline in the use of plenary guardianship measures (AJuPID, 2016).

Also, reflecting the influence of the UN CRPD (2006) and the efforts of countries that have ratified the CRPD to comply with requirements of article 12, there is a trend in Europe towards moving away from proxy to assisted/supported decision-making approaches. Article 12 places an obligation on countries to provide access to the support necessary for the exercise of legal capacity. This should include supporting the person in making decisions for specific issues, and also adapting legal instruments (e.g. powers of attorney and advance directives), in order to extend legal agency of the person, in cases where the person lacks capacity to make decisions even with support (Martin et al., 2016). Some of the most recent legislation in the field of legal capacity has been guided by a rights-based approach and has put a great emphasis on promoting the right to self-determination and autonomy of the person. These approaches move away from regarding public protection as the main priority, towards an approach that safeguards and promotes the rights and dignity of the person, and highlights the need to balance care and protection against empowerment and the individual's rights. These systems also need to ensure adequate and proportionate protections to the person and to others.

These recent reforms may suggest a shift from a paternalistic and protectionist understanding of legal capacity to an approach based on promoting personal autonomy and choice. This may be particularly useful for people living with dementia as their condition is marked by a progressive decline of their cognitive functions, and this would suggest that these the legal mechanisms allow for a gradual response.

However, the implementation of some of the principles embedded in the legislation, does not come without challenges. Several questions may arise about how these principles could be implemented in practice, and often the law may not provide specific details of how to address such challenges. Some examples include the question of how best to interpret the will and preferences of people who are at advance stages of dementia, particularly if the will and preferences are not clear, may have changed or there are contradictory expressions of will and preferences over time. Another challenge could be around what “practicable steps” need to be taken to assess that a person lacks capacity. A good example of detailed information on this was found in the new Act in Northern Ireland, where such “steps” are spelt out in the Act. It will be interesting to follow the implementation of these provisions in the field of dementia. Also, challenges may exist when there are discrepancies between the wishes of the person and the opinion of the guardian. Sometimes, due to different circumstances, there may be difficulties for respecting the wishes expressed by the person at the early stages. The personal accounts presented in this report, from a very small number of people with dementia and their carers, could offer a glimpse of the various challenges that making decisions on behalf of a loved one may pose.

As recommended by Martin and colleagues (2016) and by the ASI (2016), statutory advocacy services should be funded and available. Independent advocates “could play a vital role in ensuring that the person’s will and preferences in a matter are identified and articulated, and that the voice of the disabled person is heard in the decision-making process” (Martin et al. 2016:28). The availability of these advocacy services could be particularly relevant in the case of dementia, as due to the symptoms of the dementia and the stigma surrounding it, some people with dementia may be at a disadvantage when it comes to communicating their needs and wishes and asserting their rights (ASI, 2016:13).

The implementation of the principles embedded in the legislation also requires a cultural change in the way dementia is perceived by, among others, health care and legal professionals and by the general public, and to tackle the stigma

associated with dementia. As an example of the need of such changes, in England, the House of Lords Committee’s Report (2014:6) on the Mental Capacity Act suggested that its implementation “has not met the expectations that it rightly raised. The Act has suffered from a lack of awareness and a lack of understanding”. Among other aspects, this report concluded that whilst the Act was “a visionary piece of legislation for its time” the principle of capacity has not always been understood by social and healthcare professionals. It was stated in the report: “The concept of unwise decision making faces institutional obstruction due to prevailing cultures of risk-aversion and paternalism. Best interests’ decision making is often not undertaken in the way set out in the Act: the wishes, thoughts and feelings of the person are not routinely prioritised. Instead, clinical judgments or resource-led decision making predominate” (2014:8). It is thus of great relevance that the work in the legal field is accompanied by work in raising awareness of dementia; in changing perceptions and attitudes towards dementia, including the perceived stigma of the illness; and in providing adequate training to the professionals that are in direct contact or are involved in assessing or making judgments about the mental capacity of people with dementia.

In addition, the right to legal capacity cuts across many other legislative domains. The report has showed different ways in addressing the rights of people with dementia when exercising different rights. Election law, family law, contract law, criminal law, banking law, medical law and mental health law are all areas which may well need to be examined for compliance with the recommendations of the different international recommendations (e.g. the Council of Europe and the UN).

Finally, the timely diagnosis of dementia is a key element for the implementation of these changes. This report has emphasised the relevance of timely diagnosis and appropriate disclosure of the disease and prognosis to the person, and of access to information about the existing mechanisms and measures. Carers of people with dementia would equally need information, and as the condition progresses and the carer may need to make more decisions on behalf of the person, perhaps also training and support.

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## Appendix 1: Legislation on Advance Directives (AD) across Europe

Country	Year of law	Scope of an AD	Legally binding?
<b>Austria</b>	2006	Medical treatment: extension of treatment (e.g. mechanical ventilation, resuscitation, nutrition), pain therapy, etc. If refusing any treatment, the treatment has to be concretely described.	It can be laid down in binding or non-binding form. To be binding it needs to comply with all requirements.
<b>Belgium</b>	2002	– Consent or refusal to certain types of treatment, donation of organs or tissue, participation in clinical trials, euthanasia. – Appoint a representative for consenting to treatment on his/her behalf should the person become incapable.	Wishes to refuse a treatment should be respected. No legal obligation for euthanasia.
<b>Croatia</b>	2015	The person can designate the person who will be able to make decisions about the person's admission to a psychiatric hospital, and to diagnostic and treatment procedures.	
<b>Czech Republic</b>	2011 <sup>1</sup>	– Approval or refusal of health care treatments.	Yes, but it cannot lead to practices, resulting in an active cause of death, or harming any other person. Also if there is a new treatment that has not been known in the time of AD origin.
<b>Denmark (Health Act)</b>	2014	Wishes regarding medical treatment. Refusal of life prolonging treatment would not be desired if: <ul style="list-style-type: none"> <li>• terminally ill</li> <li>• or in case of illness, advanced debilitation due to old age, accidents, heart failure or similar situations where that the person would be permanently unable to take care of him/herself</li> </ul>	Only legally binding if the person is terminally ill.
<b>Finland</b>	1993	Medical treatment, according to jurisprudence it can cover: treatment of medical conditions, care and welfare decisions, research, life supporting/ saving treatment and the appointment of a health care proxy. Some include details of what the person likes to eat/drink, who the person likes to dress, etc.	In case of emergency AD are binding, and it is considered as a good practice to comply with them.
<b>France</b>	2005	Wishes of the person concerning the conditions to limit or stop treatment at the end of life.	AD are not binding, but are important for taking medical decisions.
<b>Germany</b>	2009	Medical investigation, treatment and /or medical intervention.	In certain circumstances are binding.
<b>Ireland</b>	2015	Type and extent of medical or surgical treatment (e.g. all therapeutic, preventative, diagnostic and palliative interventions, including life-sustaining treatment) that the person wants in the future, and/or to appoint a healthcare representative to ensure that the terms of the AD are complied with.	Requests for treatment are not legally binding. Treatment refusals, including the refusal of life-sustaining treatment, are as effective as they would be if the person making the refusal currently had capacity.

<sup>1</sup> Advance Directive in Health Care.

Requirements	Where it should be kept	Duration
<p>The person must consult a doctor (who provides information, confirms that the person has capacity and understands the consequences of the AD).</p> <p>The document has to be signed by the doctor.</p> <p>Presence of a lawyer or notary.</p>	In the person's clinical records (if in hospital) or in medical history.	5 years.
In order to be binding the refusal to treatment has to be in written, the person has to have capacity, but this is not formally assessed.	In the medical records. It is up to the person or his/her representative to ensure that the AD is known to the doctor.	Not limited. However, in the case of an AD made specifically requesting euthanasia in the case where a person is unconscious and suffering from an irreversible medical condition, the AD must have been made in the last 5 years.
<p>– Written document, dated and signed by patient.</p> <p>– It needs to be done before a notary.</p>	In central registry.	Not limited.
<p>It must contain written information about the consequences of the decisions.</p> <p>The person has to have capacity.</p>	Medical documentation.	Not limited.
<p>Capacity is presumed.</p> <p>The document has to be sent to a Central Registry.</p>	Central registry. If a health professional is considering giving life prolonging treatment to a person who is unable to consent, he/she must consult the living will registry to check whether the person has made one will.	Not limited.
AD may be verbal or written.	The AD should be recorded and kept in the medical file or remain in the person's possession. The AD can be connected to the electronic patient database. The AD can be expressed keeping with the AD card that tells of its existence.	
Written document, dated and signed.	The directives can be kept in the medical file for easy access, or remain in the person's possession or his/her healthcare proxy ("personne de confiance").	3 years.
<p>Written document.</p> <p>Advice from a doctor and confirmation of capacity by a notary are advised but not obligatory</p> <p>If the medical treatment /intervention is not clearly described, it is not effective.</p>	The advance directive should be kept in the medical file and in the possession of the healthcare proxy. There is also a central register.	Not limited.
<p>Shall be in writing and has to be signed by the person, the designated healthcare representative (if any) and two witnesses.</p> <p>The treatment that the person would like to be provided or would like to refuse has to be specified.</p>	.	

Country	Year of law	Scope of an AD	Legally binding?
Jersey	2016	According to the new Capacity and Self-determination Law (2016) advance decisions can be made about specified treatments that the person does not want to be carried out or continued by a person providing health care.	
Latvia	2009	Consent or refusal to a medical treatment.	
Luxembourg	2009	End-of-life treatment and care, also possibility to designate in advance a trusted person who doctors should consult about end-of-life decisions.  This might include the conditions, limits and withdrawal of treatment, including the treatment of pain, as well as psychological and spiritual accompaniment that s/he would like to receive.	If the doctor decides not to follow the will, it has to be documented and the trusted person informed.
Netherlands	1994	Opinion on withholding consent and refusing treatment, including not to be resuscitated.	Legally binding unless "well-founded" reasons.
Norway	1999	Right to health care treatment and to be both consulted and asked. All conditions, care and welfare on national and local level. Possibility to designate health care proxy.	Yes.
Portugal <sup>2</sup>	2012	Health care treatment that the person wants or not to receive and/or designate a health care proxy. It may include: artificial support of the vital functions, futile or useless treatments (basic support of life, artificial feeding or hydration, experimental treatments), adequate palliative care and permission or refusal to participate in research or clinical trials.	It shall be respected unless it can be demonstrated that the person would not have wanted to follow it or if it is outdated.  If not respected the decision has to be documented.
Slovenia	2007	Refusal of treatment in the case of terminal illness or if the person suffers from a disease for which treatment will only need to prolong life. Also a health representative can be designated.	Only binding in case of terminal illness if the treatment would not lead an improvement of his/her health or alleviation of symptoms.
Switzerland	2013	Type of medical treatment or care that the person would or would not like to receive. Also possible to designate a person who would be responsible for making decisions.	It should be respected unless there are doubts of its validity or reasons to believe it no longer corresponds with the person's wishes.  If not respected, doctor must document the decision on the medical file.
UK: England and Wales	2005	Treatment of medical or psychiatric conditions; care and welfare conditions, life-supporting/saving treatment, research. Also possible to designate a health care proxy. It cannot contain refusal of basic care, the offer of food/drink or request for euthanasia.	To be binding it must be clear, unambiguous and relevant.
UK: Scotland	2000	Treatment of medical or psychiatric conditions; care and welfare research.	Not legally binding however, codes of practice to Adults with Incapacity Scotland Act states that "An advance statement which specifically refuses particular treatments or categories of treatment is called an 'advance directive'. Such documents are potentially binding. When the practitioner contemplates overriding such a directive, appropriate legal and ethical guidance should be sought".

<sup>2</sup> The new Bill in Portugal (which has not yet come into force) proposes a new possibility of planning in advance care and other personal, property or financial affairs. When the person becomes incapable and the mandatory needs to start acting on the person's behalf, he/she has to communicate it to the Court. Only after this communication is conducted, the exercise of the mandate is legal.

Requirements	Where it should be kept	Duration
An advance decision is not applicable to life-sustaining treatment unless – (a) it is verified by a statement by the person that it is to apply to that treatment even if the person's life is at risk; (b) it is in writing signed by the person or by another person in the person's presence and at person's direction; (c) the signature is made or acknowledged by the person in the presence of a witness; and (d) the witness signs the decision in person presence.		
In the presence of a lawyer or notary.		
In writing, dated and signed by the patient.	Person's medical or care files.	Not limited.
In writing. The identity of the person and validity of the document should be certain.		Not limited.
Written, or it can be an oral statement. Notes in personal medical file.	Central registry.	Not limited.
It has to be signed in front of a notary/deposited in the Living Will National Registry. It can also be done directly in the Living Will National Registry.		5 years.
In the AD it must be stated that the person has legal capacity and must be signed by the person and contain details of his/her doctor and designed health representative.	Medical card or file.	5 years.
Document must be in writing and signed. The expressed will has to be precise.	Its existence and the deposit location may be recorded on the insurance card. The doctor must find out if the person has an AD.	Not limited, but it is recommended to review it regularly.
Can be oral but if it refuses life-sustaining treatment it must be in writing, signed and witnessed.		Not limited.
Codes of Practice state "A competently made advance statement made orally or in writing to a practitioner, solicitor or other professional person would be a strong indication of a patient's past wishes about medical treatment but should not be viewed in isolation from the surrounding circumstances.	May be recorded in medical records. Mental Health (Scot) Act 2015 requires NHS Boards to keep a copy of an Advanced Statement made under and for the purposes the Mental Health (Care and Treatment (Scotland) Act 2003.	Not limited but the status should be judged in the light of the age of the statement.


## Appendix 2: Powers and obligations of guardians

Country	Scope/powers	Administrative obligations/responsibilities
<b>Austria</b>	As specified in Court Order. It can include financial affairs and welfare. The trustee cannot make "strictly personal decisions" (e.g. place where the person lives or related to the right to bodily integrity).	Assets should be used to improve the person's living conditions.  The trustee has to report to the Court on contacts with the person, the person's housing and living conditions at least once a year and on financial affairs every 3 years.
<b>Belgium</b>	As specified in Court Order. Patrimonial and non-patrimonial rights. Certain rights cannot be exercised by the administrator, these include among others: consent to marriage, divorce or separation, determination of the conjugal domicile, issues related to parenthood such as adoption or recognition of parenthood, request for euthanasia, making or revocation of testamentary dispositions, the exercise of political rights.	The administrator must exercise his/her functions diligently and is responsible for supervising the expenses of the person.
<b>Bulgaria</b>	Welfare, administration and representation.	The guardian must inform the Organ of the full guardianship and trusteeship /OGP/ of acquisition of property and needs permission from the Court to withdraw money from bank deposit.
<b>Croatia</b>	As specified in Court Order. Certain acts cannot be exercised by the guardian, some examples include: consent to marriage or divorce, issues related to parenthood such as acknowledgment of paternity or adoption, other strictly personal issues (e.g. consent to sexual relationships).  Some medical decisions need special permission from the court: termination of pregnancy, sterilization, donation of tissues and organs and measures of life support.	
<b>Cyprus</b>	Legal and financial affairs.	
<b>Czech Republic</b>	As specified in Court Order. Is not allowed to make a will on behalf of the person.	In some cases the guardian may need an insurance against harm he/she may cause to the person under guardianship.
<b>Denmark</b>	As specified in Court Order. It does not include decisions concerning everyday life such as shopping, cleaning, etc.	If the guardian manages the finances he/she must ensure that the money is used for the benefit of the person.
<b>Finland</b>	Welfare, administration and representation. In some cases, the guardian can be authorised by court to take decisions related to treatment.  Guardians cannot agree to marriage, adoption, admit paternity, make or cancel a will or other affairs of an equally personal nature.	The guardian must conscientiously protect the finances of the person, preserve assets that are needed for living and invest the remaining in a way that a reasonable profit is attained.  Guardians should ensure that the person receives treatment, care and rehabilitation as appropriate.
<b>France</b>	As specified in Court Order. It is not possible to make decisions that are "strictly personal" on behalf of the person.  In case of curatorship, the curator cannot take the place of the person.	The guardian should submit a report yearly to Court about the management of the finances.

Country	Scope/powers	Administrative obligations/ responsibilities
Germany	Guardianship ("rechtliche Betreuung") includes different areas and can be split among several persons. Main areas are: Finances, Medical issues, Decisions about residence and move to nursing home.	Guardians always have to act in the best interest of the person they care for.  In some areas, e.g. decisions about residence, guardians need the agreement of the appropriate Court.  Guardians have to give a report to the Court every year, especially about financial matters.
Greece	All legal acts.	All acts carried out by the legal counsellor are under supervision of a Board composed of 3–5 family members or friends.
Ireland	As specified in Agreement. A decision-making representative: <ul style="list-style-type: none"> <li>• shall not exercise any power (including the power to consent) vested in the person</li> <li>• shall not do an act that is intended to restrain the person</li> <li>• cannot be given the power to prohibit a particular person from having contact with the person</li> </ul>	
Italy	As specified in Decree. Including those that have to be done jointly and those that the guardian can do on behalf of the person. The amount of money that can be spent should be specified.  The person always retains capacity for carrying out everyday life activities (shopping, etc.).	He/she should evaluate and notify the Court the needs of the person and represent him/her with the purpose of handling his/her affairs in accordance with his/her powers.
Jersey	Some types of decisions should never be made by another person or a court, on behalf of another person who lacks capacity. This is because these decisions or actions are either so personal to the individual or because other laws govern them. Examples include decisions relating to marriage or civil partnership, divorce, sexual relationships and voting.	
Latvia	As specified in Court Order.	
Lithuania	As specified in Court Order.	The guardian should ensure that assets are used exclusively in the interest of the person.
Luxembourg	Mainly financial affairs.	The guardian may be asked to collect the revenue, take care of expenses and invest any excess in an account approved by the government.
Malta	Guardians can act instead of the person in matters of personal or proprietary nature and do any other thing for or on behalf of the person to whose guardianship they are appointed.	Guardians shall within 2 months of appointment submit to the Board a list of the person's assets and liabilities.  Guardian should ensure that the welfare of the person is promoted and fostered.  The guardian shall act in the best interest of the person.
Monaco	Tutor: administrative decisions (mainly financial affairs).	
Netherlands	As specified in Court Order.  If the person objects to medical decisions taken by the guardian, they will only be adhered to if it is necessary to avoid serious harm.	The guardian may place at the disposal of the person sums of money which s/he may use for the purpose of maintenance, e.g. to buy food and clothes.

Country	Scope/powers	Administrative obligations/ responsibilities
Norway	Mainly financial affairs. Family members can be appointed.	Appointed from the County Governors on regional level. Guardians must report on finance and tax issues annually. National supervision with separate legal body: Vermålsforvaltningen.
Poland	Welfare (including decisions about health and treatment), administration and representation.	The guardian needs to ask permission from court for any important decision concerning the person The guardian has to submit a financial report to the Court annually.
Portugal	Health, administration and representation.	
Romania	As specified in Court Order.	
Slovakia	As specified in Court Order. The guardian must for all cases manage the property of the person.	The guardian shall perform his/her functions diligently.
Spain	Welfare and administration in the case of full guardianships, in partial guardianships as specified in Court order Unless otherwise specified in the Court Order the person under guardianship retains the right to vote, to get married, to make testament and to sign an employment contract.	The guardian needs to ask permission from court for any important decision concerning the finances or property of the person.
Sweden	Custodian: always include management of finances, also ensure the person receives care and supervision. Trustee: as specified by Court.	Within a month of appointment the custodian/trustee has to submit an inventory of the assets and liabilities of the person. The custodian should contact any suppliers (e.g. Telephone Company, insurance, etc.) so that bills are sent to the correct address.
Switzerland	Personal welfare, management of his/her assets or legal matters. For some important transactions/acts the consent of the Adult Protection Authority is required.	In fulfilling his/her tasks, the deputy shall have the same duty of care as an agent under the provisions of the Code of Obligations. The deputy shall carry out his/her tasks in the interests of the client, take account of the client's opinions, where possible.
Turkey	Welfare, administration and representation.	The guardian must keep record of the administration and submit report to court regularly.

Country	Scope/powers	Administrative obligations/ responsibilities
UK: England and Wales	<p>Two different types of deputies: for property and financial affairs and/ or for personal welfare. The deputy can apply for one or both.</p> <p>There are some decisions that can never be made under the Act by another person for someone who lacks capacity. Decisions that cannot be made on behalf of someone else include: whether to get married or have a civil partnership; whether to have sex; placing a child for adoption; and voting at an election.</p> <p>Deputies cannot:</p> <ul style="list-style-type: none"> <li>• restrain the person, unless it's to stop them coming to harm</li> <li>• stop life-sustaining medical treatment</li> <li>• take advantage of the person's situation</li> <li>• make a will, or change an existing will</li> <li>• make gifts (unless specified in court order)</li> <li>• hold any money or property in the name of the deputy on the person's behalf</li> </ul>	<p>Deputies are asked to take out insurance for their decisions in the form of a security bond.</p> <p>The deputy could be fined or sent to prison for up to 5 years (or both) if the deputy mistreats or neglects the person on purpose.</p> <p>Deputies must write a report each year explaining the decisions that has made as a deputy.</p>
UK: Scotland	<p>Guardianship orders can cover property and financial matters or personal welfare, including health, or a combination of these. The types of decisions that are to be taken on behalf of the adult will determine the powers that should be granted, such as:</p> <ul style="list-style-type: none"> <li>• finances and property</li> <li>• welfare</li> <li>• combination of financial/property and welfare – powers, if required can be applied for separately but generally they are made together within the same application to the sheriff court</li> </ul> <p>An intervention order would be suitable where there is a single action, series of connected actions or decision(s) to be taken on behalf of the adult. Intervention orders can cover both financial and welfare matters.</p>	<p>There are certain decisions which can never be made on behalf of a person who lacks capacity to make those specific decisions. This is because they are either so personal to the individual concerned, or governed by other legislation. For example consent to marriage or making a will are not matters where an intervention under the Act would be competent.</p> <p>Financial Guardians are required to provide an inventory of financial assets, a financial management plan, and annual accounts to the Officer of Public Guardian in Scotland.</p>

The background of the page is a solid blue field with several large, white, five-pointed stars arranged in a circular pattern, mimicking the design of the European Union flag.

The 2016 Dementia in Europe Yearbook focuses on decision-making and legal capacity issues in dementia. The report provides an overview of how legislation regulates the issue of legal capacity in questions such as contractual capacity, testamentary capacity, criminal responsibility, civil responsibility, marriage and voting. It also looks at the topic of consent to treatment and research and refers to the existing legal provisions for people who are not able to provide informed consent, including advance directives and healthcare proxies. The last part of the report, introduces the topic of substitute decision making and provides an overview of guardianship measures across Europe. It covers, in particular, court-appointed guardians and lasting powers of attorney. 31 countries have participated in this comparative report, including most Member States of the European Union as well as Jersey, Monaco, Norway, Switzerland and Turkey.