

# Dementia in Europe Yearbook 2023

Legal capacity and supported decision-making related to dementia





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# 1. Preface



It gives me great pleasure to introduce the Dementia in Europe Yearbook 2023, which this year focuses on legal capacity and supported decision-making for people with dementia across Europe.

The last Dementia in Europe Yearbook to examine this subject was published in 2016 (“Decision-making and legal capacity in dementia”), at a time when a number of countries were reforming or examining their own legislation. At that time, the General Comment No.1 (on Article 12 of the United Nations Convention on the Rights of Persons with Disabilities [UNCRPD]) posed a direct challenge to much of the existing national legislation and thinking around systems of substitute decision-making, with the General Comment calling for systems of substitute decision-making to be replaced by systems of supported decision-making.

Whilst this move towards supported decision-making is welcome, Alzheimer Europe has previously identified in its work, including the Ethics Report on decision-making and capacity from 2020, that such an approach may sometimes be impractical and fail to understand experiences of people living with dementia, their families and carers. Where a person with a progressive illness such as dementia experiences ongoing cognitive decline, it is often the case that their ability to understand information, make decisions and communicate will at some point reach a stage where even with intensive support, supported-decision will not be possible. Alzheimer Europe’s position continues to advocate for a combined supported decision-making model which makes supported-decision the basis for systems of legal capacity, but which also recognises the necessity and importance of substitute decision-making in certain instances.

Since the publication of the 2016 Yearbook, there have been further developments at a European and International level, including the European Commission’s proposals in relation to the Hague Convention on the Protection of Vulnerable Adults 2000, as well as a General Comment No.6 (on Article 5 of the UNCRPD), which have advanced the discussions within the field of disabilities and across different domains of policy. However, these have not resolved some of the underlying conflicts between the objective of the UNCRPD to abolish substitute decision-making

and the need for substitute decision-making to exist where a person lacks the ability to make these decisions themselves.

Indeed, this is evident in the findings of the Yearbook 2023 where it is apparent that even in countries which have reformed or made changes to their legislation relating to substitute and supported decision-making. Ireland’s reform has attracted much attention and interest, owing to its embedding of a model of supported decision-making and the overview body the Decision Support Service in upholding the legal capacity of individuals. As the legislation has only taken effect this year, its operation will be closely followed by other countries seeking inspiration for their own laws. However, other countries have also reformed their legislation since the development of the UNCRPD and a number have tiered approaches to guardianship/powers of representation which, whilst not as holistic in approach as the Irish system, have managed to embed proportionality and maximise the autonomy of the person to a significant degree.

Yet it is interesting to note new legislation in these countries does not completely abolish substitute decision-making – there are still provisions for the use of court appointed guardians where the person is unable to make decisions regarding their own affairs.

Despite the lack of significant developments in

legislation, there is a demonstrable and welcome shift in the policies and resources which surround legal capacity and decision making, and we are happy to share some of the excellent resources produced by our members, national governments and other organisations throughout the report. We hope these will prove useful for other organisations and governments seeking information and resources.

Additionally, we are grateful to members of the European Working Group of People with Dementia (EWGPWD) and, for the first time since its establishment, the European Dementia Carers Working Group (EDCWG), for sharing their experiences and views. This is a difficult and emotive subject, however, the contributions of people with dementia and carers are a clear expression of how these systems work in practice – indeed there is an evident need for more support from professionals for families to have these

conversations (especially at the time of diagnosis), as well as better promotion of the value of making such arrangements amongst the general population, instead of waiting until circumstances necessitate it.

Finally, I wish to thank our members for their contributions, without whom, this publication would not be possible. I would also like to acknowledge the work of our Policy Officer, Owen Miller, for his work in compiling this information and writing the Yearbook.

**Jean Georges**  
**Executive Director**  
**Alzheimer Europe**



## 2. Introduction

### 2.1. Background to this report

Alzheimer Europe has visited the subject of legal capacity and decision-making before in its work, including:

- The LАWNET project (1998) and LАWNET II (2009)
- The Dementia in Europe Yearbook 2010 (focused on legal capacity and proxy decision-making in dementia)
- The Dementia in Europe Yearbook 2016 on decision-making and legal capacity in dementia.

The first LАWNET project established a comprehensive baseline setting out the legal context for persons with dementia in relation to legal capacity, with the 2010 and 2016 Yearbooks providing updates on the emerging picture across Europe.

Since the publication of findings of the LАWNET project 25 years ago, the discourse around decision-making and, in particular proxy decision-making has evolved considerably, with concepts of proxy decision-making to act in an individual's best interests coming to be seen as insufficient to uphold the rights of the person and to support their exercise of autonomy and agency. The focus has since shifted toward the concept of supported decision-making, utilising the capacity and abilities a person retains (rather than those which the person has lost), whilst also examining how information, questions and choices are presented to a person.

The complexity of capacity is down to a number of different elements:

- The fluctuating nature of capacity, which may change day to day (depending on the type of dementia, other conditions which affect cognition etc.)
- Decision-specific decision-making across different contexts (e.g. a person may not be able to make decisions on financial matters but may still be able to decide about their daily activities or care matters)

- The emergence of supported decision-making as a concept, the move away from proxy/substitute decision-making and the challenges around the implementation of this in different settings (including non-clinical care settings or among non-clinical staff)
- The different types of legal capacity (e.g. contractual testamentary etc.), the exercise of political and civil life rights (e.g. voting, marriage etc.), as well as decisions-making in relation to treatment and research.

The Dementia in Europe Yearbook aims to provide an updated snapshot of the current situation in relation to these different aspects across Europe, highlighting examples of good practice in law, policy or practice, as well as reflecting the views of people with dementia, their families and carers through testimonies from the European Working Group of People with Dementia (EWGPWD) and the European Dementia Carers Working Group (EDCWG).

### 2.2. Methodology

In March 2022, at a public affairs meeting attended by Alzheimer Europe's national member organisations, Alzheimer Europe presented the policy context, whilst also setting out its proposed approach for the 2023 Yearbook, its structure and a proposed timeline, inviting comments and input from members.

Following this meeting, a small group of members were invited in April 2023 to help contribute to the development of a questionnaire which would be sent to members, with this group helping to shape the approach and questions within the survey.

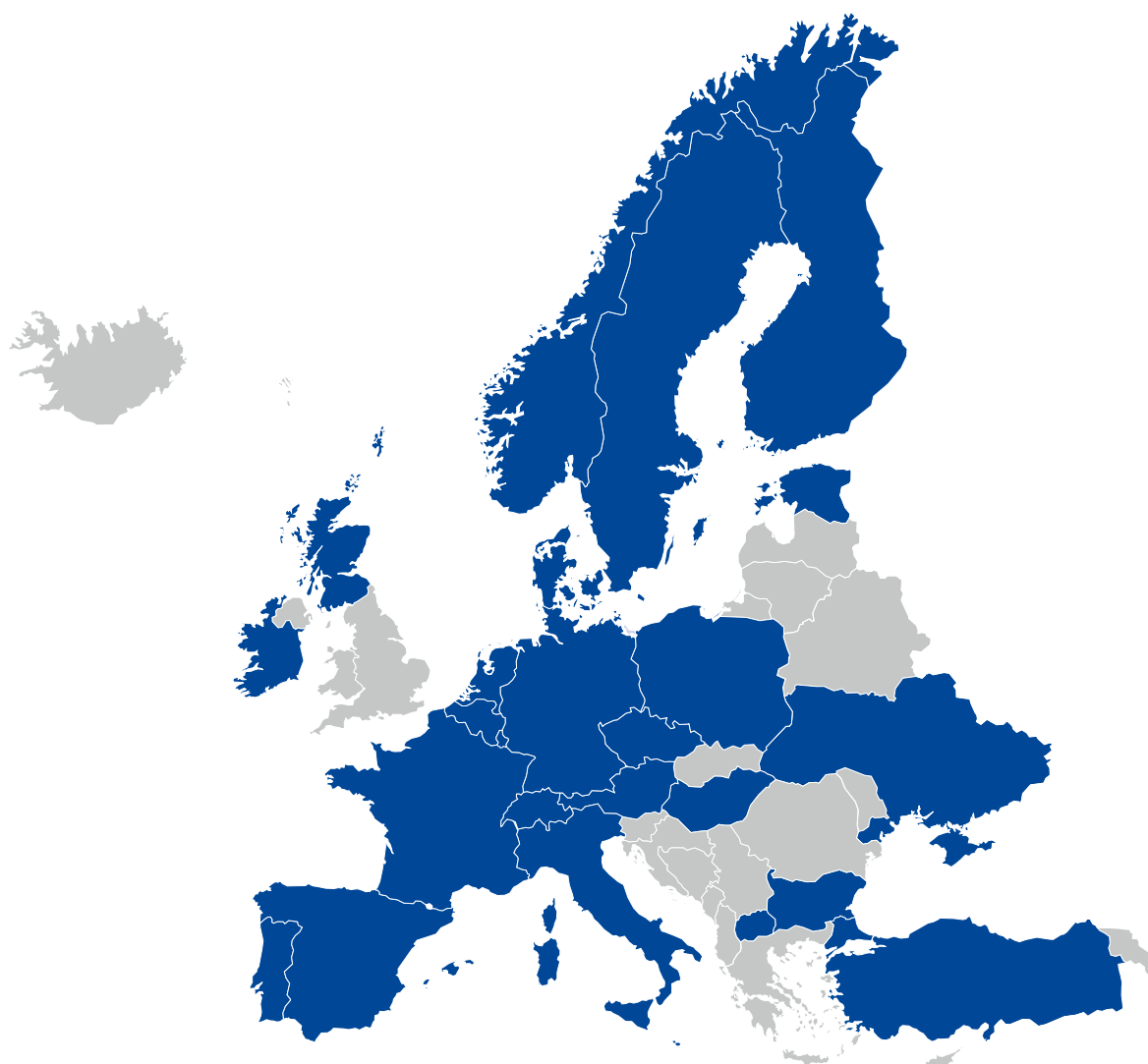
In April 2023, Alzheimer Europe distributed the survey to its member organisations, with deadline set for receipt by the end of June 2023. In total, Alzheimer Europe received 27 responses, from 25 countries (two responses were received for both Poland and Spain).

Alzheimer Europe analysed the findings from the completed surveys, identifying overarching trends and themes, as well as examples and resources which may

be of interest to other organisations working in the field of dementia. Members were given an opportunity to review a draft text of the report late in 2023.

### Countries who responded to the survey

Austria	Hungary	Portugal
Belgium	Ireland	Spain
Bulgaria	Italy	Sweden
Czech Republic	Luxembourg	Switzerland
Denmark	Malta	Turkey
Estonia	Netherlands	Ukraine
Finland	North Macedonia	United Kingdom - Scotland
France	Norway	
Germany	Poland	



### 2.3. Caveats to this report

The findings in sections 5 through 10 reflect the information received through the survey responses, which were completed by our national member organisations. The good practice examples and resources included within this report in section 11 are those which have been suggested by our members. The process for the development and distribution of the survey is outlined in the previous subsection.

The complexity of laws relating to legal capacity, as well as instances of cross-border protections, is difficult to encapsulate in a single report. The way in which laws are intended to function, how they operate in practice and the experience on the ground will vary significantly both between and within countries.

In order not to omit key details of laws or policies, Alzheimer Europe has included the information

received in the survey responses as fully as possible. Where a country, is omitted in a section, it was because the country either had no activities in this area (for example, the country does not have a national dementia strategy) or did not provide information.

In the conclusions section, we have reflected on the common themes emerging between the different countries, as well as noting what this means for legal capacity and the rights of people living with dementia, including in the context of the UNCPRD. Where there are gaps or significant issues, these have been addressed in the recommendations.

Finally, it is important to note that the existence of policies or legislation in a country, for example within a dementia strategy or other policy document, does not guarantee that the specific measures are being implemented or universally applied across that country.



## 3. Defining capacity and decision-making

Many of the ethical issues around capacity and decision-making have previously been explored in-depth in Alzheimer Europe's ethics report "Legal capacity and decision-making: The ethical implications of lack of legal capacity on the lives of people with dementia", which was published in 2020.

As such, this section will not examine in detail all of the concepts and underpinning ideas of capacity and decision-making. Instead, it will provide an overview of some key concepts which will be identified in the national, European and International policies and legislation in the following sections of the Yearbook.

Whilst the different types of capacity (mental and legal) are evidently interconnected, they have distinct elements and implications for the person and their lived experience. Specifically, the way in which decisions are made by or for (in the case of substitute decision-making) the individual determine the extent to which we can consider that their rights as an individual are being respected and upheld.

As such, this section will briefly provide an overview of the difference between mental and legal capacity, briefly considering what this means in practical terms (e.g. the assessment of capacity). Additionally, it will set out the key points of substitute decision-making and supported decision-making.

### 3.1. Legal capacity and mental capacity

The concept of legal capacity refers to the recognition of a person as a holder of rights and obligations before the law, which includes the possibility of creating and terminating legal relationships with others. As has been articulated by the European Agency for Fundamental Rights, this 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. Examples of this include, entering into a contract, giving or refusing consent to medical treatment. There the legal capacity is fundamental to a person's freedom and self-determination, as well as being the foundation for the exercise of civil, political, economic, social and cultural rights.

By comparison, mental capacity refers to the ability of an individual to make decisions, including understanding information relevant to the decision, ability to communicate a decision and comprehension of the consequences of the decision. The ability of a person to make a decision may depend on its complexity (e.g. the person may be able to take decisions on activities and day to day living, but may find it more challenging to take decisions relating to complex financial matters). Additionally, capacity can be considered as fluctuating, and may change day to day or indeed, may change depending on the time of day, as well as being temporarily affected by factors such as confusion, fatigue or medication.

### 3.2. Assessment of mental capacity

There are different approaches to the assessment of mental capacity, which can be broken down into the status, outcome and functional approach:

- 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 model of disability diagnosis of impairment.
- Outcome approach – an individual's legal capacity is denied or restricted based on the perception that the individual has made a poor decision. To some extent, this approach resembles the status approach insofar as a diagnosis of disability (or cognitive impairment), may mean that the decision-making skills of the person may immediately be questioned. This is again seen as a medicalised approach, where a person's actions are seen through in relation to the disability, not the person in their own right.
- Functional approach – an assessment is carried out to determine whether, at the time of the decision, individual understands the meaning

and consequences of the issue, with assessment of the person's ability understand, retain and apply information, as well as the ability to communicate the decision to others. If it is determined that the person does not meet a prescribed standard, it is at this moment that the person is deemed not to have legal capacity.

### 3.3. Capacity is not a unitary concept

As an underpinning concept which runs throughout the discourse in this subject, it is useful to reiterate that there is no single capacity. Adults have distinct and multiple capacities, which spans a broad range of activities. For example, the legal capacity to make a will, to consent to medical treatment, to manage financial affairs or to manage their own personal affairs.

Each of these involves a combination of cognitive and functional abilities, which are distinct and set them apart from other capacities. For example, the capacities required for driving are significantly different from those for making a will.

Additionally, capacities tend to be associated or linked to certain situations or settings. Some may be regularly recurring tasks or activities in the home or in a community, whilst other may be infrequent or attached to specific contexts.

As such, it is important that when making an assessment of whether an individual has capacity to make a decision, this is done with the understanding that it is specific to the decision at that moment in time, within the context of:

- The needs of the person as a result of a condition (e.g. cognitive or sensory impairment, short term illness) that may affect decision-making
- The person's ability to understand, process and retain information
- How information has been presented to the person
- The environment in which a person is expected to make a decision
- Any other context that may impact upon a person's decision-making ability.

### 3.4. Substitute and supported decision-making

Legislation relating to legal capacity has often operated on the principle of the "best interest", viewing the person as vulnerable or in need of protection, as a result of their disability and/or cognitive issues. As such, legislation in many European countries is drafted in such a way as to provide means for decisions to be made on behalf of an individual, when it was deemed that they could not do so themselves. This covers proxy decision makers (including powers of attorney or guardianship), in addition to compulsory treatment, denial of civic rights (e.g. marriage, right to vote), amongst other areas.

Within the disability field and especially in the context of the UNCRPD and its associated documents (which is covered in greater detail in section 4), there has been a concerted effort to move away from substitute decision-making, encouraging the adoption of models supported decision-making instead.

This approach is characterised by a greater focus on the rights of the person, allowing them to make decisions themselves and giving effect to their will and preferences. As part of this, the focus shifts from the person's disability or limitations, instead examining how the persons can be supported make their own decisions, including resources and tools which might be person to make decisions themselves.

As outlined in section 4, the Committee on the Rights of Persons with Disabilities (through its General Comments and other supporting document to the Convention) has determined that substitute decision-making and legislation are discriminatory and should be abolished, especially in relation to court appointed guardianship. However, this blanket approach fails to account for situations where a person is unable to make decisions for themselves, even with additional support and resources. Whilst it does not oppose power of representation (e.g. power of attorney, advanced directives etc.) per se, it is regarded as unacceptable for arrangements to be made that take effect upon the occurrence of a particular contingency such as incapacity.

Alzheimer Europe fully supports the adoption of supported decision-making approach for people with dementia and wishes to see the reform of legislation and systems which allow for substitute decision-making as a default option and which do not mandate supporting the individual to make their own decisions. However, given the progressive nature of dementia and its effect upon the different capacities of an individual (particularly in the later stages of the illness), it is sometimes necessary for decisions to be made on behalf of the individual, for example through a guardianship or power of attorney.

Alzheimer Europe has explored this issue in some detail in the “Legal capacity and decision-making: The ethical implications of lack of legal capacity on the lives of people with dementia” report published in 2020:

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

1. *Presumption of decision-making capacity: Everyone in our society should initially be deemed competent to make their own decisions and their decisions should be treated as carrying legal effect. This also holds for people with dementia.*
2. *Rebuttal of the presumption: The presumption of decision-making capacity can be rebutted only if there are concrete indications that a person might lack decision-making capacity. A diagnosis of dementia is not enough to rebut the presumption of decision-making capacity. A diagnosis of dementia is, however, a relevant factor, since dementia is a risk factor for impaired decision-making capacity. A diagnosis of dementia should trigger an assessment of decision-making capacity only if other factors also exist, for example, the person shows abrupt changes in their mental state, refuses recommended treatment or consents to particularly risky or invasive treatment. A refusal of recommended treatment should be considered in the context of the stakes involved. This should be based on reflection about the balance between the consequences of refusal and the possible effects of treatment on the person’s health, potentially resulting in a more structured assessment of a person’s decision-making capacity.*
3. *Assessment of decision-making capacity: An assessment of decision-making capacity consists of a semi-structured conversation of 20-30 minutes about the decision to be taken. During this conversation, the assessor should assess whether the person is able to: (a) understand the potential consequences of the various options, (b) apply this understanding to their own situation, (c) evaluate the consequences of the treatment options in light of their values and commitments, and (d) communicate a treatment choice.*
4. *Supported decision-making: If the assessment shows that the person possesses the required abilities, they can make their own decisions and these decisions will carry legal effect. If, on the other hand, the assessment shows that the person’s decision-making abilities are substantially impaired, supported decision-making should be provided in order to enhance the person’s abilities and bring them in the position to make their own decisions.*
5. *As examples of supported decision-making, Scholten and Gather (2018) mention everyday interventions (e.g. giving time to adapt or providing tranquil surroundings), interventions that improve the quality of the disclosure information (e.g. enhanced consent procedures), interventions that facilitate communication (e.g. plain language, braille or sign language) and social support from family, friends or peers. Support could also incorporate elements of shared decision making, subject to the person with dementia being in favour of such support.*
6. *Monitoring: During the provision of supported decision making, the conversation about the decision to be taken should continue and it should be monitored whether the support provided enhances the person’s abilities up to a point at which they are in the position to make their own choices. In this process, it should also be monitored whether support people (consciously or unconsciously) exert undue influence on the person.*
7. *Substitute decision making: If it turns out that supported decision making enhances the person’s abilities to a sufficient extent, they can make their own decision and this decision carries legal effect. If supported decision making proves insufficient and all reasonably available resources for support have been exhausted, a substitute decision maker should make a decision on behalf of the person. The guiding question*

*for substitute decision makers is not what they prefer, nor what they would prefer if they were in the person's situation. Rather, they should ask themselves what the person would want in the situation if they had decision-making capacity. The answer to this question can be seen as the "best interpretation of the person's will and preferences".*

- 8. Evidence for the person's will and preferences is provided by (a) an advance directive, (b) previously communicated preferences with regard to the choice at hand, (c) the person's values and commitments, and (d) the person's best interest. This is a prioritised list, meaning that substitute decision makers should make decisions based on, for example, the best interest of the person only if all the other sources of evidence about the person's will and preferences are unavailable or insufficiently clear.*

## 4. Current policy context

In this section, Alzheimer Europe provides a high-level overview of the key points in relation to the current policy context at a European and International level. In particular, the section sets out key policy developments, including those relating to disabilities, employment and social protection, which have been developed and have come into effect in the past two decades.

A number of Council of Europe recommendations and conventions, as well as the United Nations Convention on the Rights of People with Disabilities (UNCRPD) 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.
- The Hague convention on the International Protection of Adults, 2000.
- Recommendation CM/Rec (2009) 11 adopting principles concerning continuing powers of attorney and advance directives, 2009, Council of Europe.
- 2012/C 326/02 Charter of Fundamental Rights of the European Union (Published in the Official Journal of the European Communities, 18 December 2000 (2000/C 364/01).
- 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.
- United Nations Convention on the Rights of People with Disabilities (UNCRPD), United Nations, 2006.

Article 8 of the ECHR, the right to respect for private and family life, protects against unjustified interference with personal integrity. The European

Court of Human Rights (ECtHR) has ruled thus also applies in relation to consent to medical treatment. Additionally, the Convention on Human Rights and Biomedicine outlines the conditions which justifies an intervention where the person does not have the capacity to consent, specifically highlights that a person's previously expressed wishes relating to medical interventions should be respected, and establishes the conditions under which research can involve persons who are deemed unable to give 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. 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 the 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.

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 co-operation between them.

## 4.1. United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

### 4.1.1. Relevant articles of the Convention

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) was adopted on 13 December 2006, opened for signatures on 30 March 2007 and entered into force on 3 May 2008.

For the EU, the Convention entered into force on 22 January 2011, with Ireland becoming the final Member State to ratify the UNCRPD in 2018. Each signatory is subject to reporting to the UN Committee on the Rights of Persons with Disabilities on a five-year cycle, with the most recent cycle of the review of the EU taking place early in 2022.

The Convention is intended to be a human rights instrument with an explicit, social development dimension, affirming that persons with disabilities must enjoy all human rights and fundamental freedoms. It clarifies and qualifies how all categories of rights apply to persons with disabilities and identifies how adaptations should be made for persons with disabilities to effectively exercise their rights.

The UNCRPD contains 50 articles in total, of which the first 30 are directly relevant to the rights of the individual. Alzheimer Europe has identified 21 articles for which this subject matter has direct or indirect relevance in relation to persons with dementia and legal capacity:

- Article 1 – Purpose
- Article 2 - Definitions
- Article 3 – General principles
- Article 4 – General obligations
- Article 5 – Equality and non-discrimination
- Article 8 – Awareness-raising
- Article 9 – Accessibility
- Article 12 – Equal recognition before the law
- Article 13 – Access to justice
- Article 14 – Liberty and security of person
- Article 15 – Freedom of torture or cruel, inhuman or degrading treatment or punishment
- Article 16 – Freedom from exploitation, violence and abuse
- Article 17 – Protecting the integrity of the person
- Article 18 – Liberty of movement and nationality
- Article 19 – Living independently and being included in the community
- Article 21 – Freedom of expression and opinion, and access to information
- Article 22 – Respect for privacy
- Article 23 – Respect for home and the family
- Article 25 – Health
- Article 26 – Habilitation and rehabilitation
- Article 29 – Participation in political and public life.

There is also an Additional Protocol to which 22 EU Member States are signatories. However, as the Protocol deals primarily with governance and operation of the UNCRPD, rather than the rights of persons with disabilities, the articles of the Protocol have not been included here.

Given the particular relevance of Article 12 for this topic, it is useful to note that Estonia, France and Poland have entered a declaration regarding their implementation of this particular article (however no EU Member States have made a reservation in relation to the article). The declarations state that they will implement the article in line with their national legislation, which in each case allows restrictions on

the right to vote of persons deprived of legal capacity, thus limiting the right to political participation of persons who have been deprived of their legal capacity.

Estonia's declaration sets out that, in its view, Article 12 does not prevent restricting a person's legal capacity "when such need arises from the person's ability to understand and direct his or her actions". Similarly, France's declaration states that legal capacity "may not be restricted except in the conditions and in accordance with the modalities provided for in Article 12 of the Convention", which it interprets as permitting a judge to deprive a person with a disability of the right to vote. In its declaration, Poland confirms it will continue to restrict the legal capacity of people with disabilities as it views such a restriction as a type of safeguard under Article 12 (4).

It is also worth noting here, that from Alzheimer Europe's other work, including its Dementia Monitor publications, we are aware that not every country recognises dementia as a disability, despite Article 1 defining it as such.

#### 4.1.2. General Comment 1 – Article 12: Equal recognition before the law

On 19 May 2014, following the 11<sup>th</sup> Session of the Committee (31 March-11 April 2014), General Comment No. 1 was published, clarifying States Parties' general obligations under Article 12 of the Convention. The Comment also highlights the relationship between close relationship between Article 12 and other articles including, articles 5,6,7,9,13,14,18, 19, 25 and 29.

Article 12 states that:

1. *States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.*
2. *States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.*
3. *States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.*
4. *States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for*

*appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.*

5. *Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.*

The General Comment expands on these points, in particular in relation to legal capacity, and proxy and support decision-making. This was done as it was felt that State Parties had failed to move away from substitute decision-making and had not reformed domestic legislation to become compliant with the Convention. Additionally, the Comment notes that many States Parties conflate legal capacity and mental capacity, discriminating against individuals with disabilities based on perceived disability or decision-making ability.

The Comment notes that whilst Article 12 allows safeguards to protect against abuse in the form of supports which allow a person to communicate their own will and preferences, including the creation of an advanced plan. However, it stresses that supports should not take the form of substitute decision-making, as these are not considered to as the exercise of legal capacity. In relation to this concept, the Comment specifically recommends the replacement of the "best interest" approach (i.e. taking a decision on behalf of the person which is felt to best for them) with the "best interpretation" approach (i.e. decision-making based on the will and preferences of the person), as a safeguard to ensure that the rights of persons with disabilities are upheld.

The general comment concludes with recommended steps for the full implementation of Article 12 at the national level. Specifically, State Parties are called on to:

- Recognise the equality of persons with disabilities before the law, including their legal personality and legal capacity.
- Abolish substitute decision-making regimes and mechanisms that deny legal capacity and which discriminate in purpose or effect against persons with disabilities.
- Establish, recognise and provide a broad range of supports for the exercise of their legal capacity – safeguards must uphold the rights, will and preferences of persons with disabilities.
- Involve persons with disabilities (e.g. through representative organisations) in the development and implementation of legislation, policies and other decision-making processes which relate to Article 12.
- Undertake and devote resources to the research and development of best practices.
- Develop mechanisms to combat both formal and informal substitute decision-making. To this end, the Committee urges States parties to ensure that persons with disabilities have the opportunity to make meaningful choices.

#### 4.1.3. General Comment 6 – Article 5: Equality and non-discrimination

On 26 May 2018, following the 19<sup>th</sup> Session of the Committee (14 February-9 March 2018), General Comment No. 6 was published clarifying States Parties' general obligations under Article 5 of the Convention. The Comment also highlights the relationship between close relationship between Article 5 and other articles including, Article 6, 7, 8, 9, 11, 12, 13, 14, 15, 16, 17, 19, 23, 24, 25, 27, 28, 29, 31 and 32.

Article 5 of the Convention states:

1. *States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.*

2. *States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.*
3. *In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.*
4. *Specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention.*

The General Comment notes that the broadening of anti-discrimination laws and human rights frameworks has led to extended protection of the rights of persons with disabilities in many countries. However, it also notes that laws and regulatory frameworks remain imperfect, incomplete and/or ineffective, with some failing to reflect an inadequate understanding of the human rights model of disability.

Specifically, the General Comment was developed as a result of the Committee's concern that a medical model of disability continued to be applied (the status/outcome approach identified in section 3), despite the incompatibility of those models with the Convention. The persistent use of such models is noted as failing to acknowledge persons with disabilities as rights holders.

The document identifies a number of actions that States Parties should take in order to ensure the full implementation of article 5 of the Convention, including:

- Incorporating disability in anti-discrimination legislation and/or enacting disability-inclusive anti-discrimination legislation providing effective legal remedies, in cases of institutionalisation, denial or restriction of legal capacity, denial of alternative modes of communication etc.
- Ensuring that protection from discrimination for persons with disabilities has equivalent standard as for other social groups and includes all forms of discrimination such as direct and indirect discrimination, harassment and intersectional discrimination.



- Establishing accessible and effective redress mechanisms and ensure access to justice, on an equal basis with others, for victims of discrimination based on disability, including access to effective judicial and/or administrative procedures, as well as in relation to civil political, economic, social and cultural rights.
- Raising awareness across all parts of society about non-discrimination and equality of all persons with disabilities, with a view to addressing the different types of discrimination, such as stereotyping and stigmatisation.

## 4.2. The Charter on Fundamental Rights

The Charter of Fundamental Rights of the European Union outlines the key personal freedoms and rights enjoyed by citizens of the EU into a single legally-binding document. The Charter was declared in 2000, and came into force in December 2009 along with the Treaty of Lisbon.

The purpose of the Charter is to promote human rights within the EU. Many of the rights that are contained in the Charter were previously set out in the EU Treaties, the European Convention on Human Rights and various case law of the Court of Justice of the European Union. These contain 54 articles, spread across seven titles, including:

- Dignity
- Freedoms
- Equality
- Solidarity
- Citizen's rights
- Justice
- General provisions governing the interpretation and application of the Charter.

As with the section on the UNCRPD, the following articles taken from the Charter are those we consider as having the greatest relevance for people living with dementia and their carers, in the context of legal capacity and decision-making.

### Dignity

- Article 1 – Human dignity – everyone has the right to be treated with dignity.
- Article 3 – Right to integrity of the person – this includes medical consent and the prohibition of certain genetic practices.
- Freedoms
- Article 6 – Right to liberty and security.
- Article 7 – Respect for private and family life.
- Article 8 – Protection of personal data.
- Article 9 – Right to marry and right to found a family – guaranteed in accordance with national laws.
- Article 10 – Freedom of thought, conscience and religion.
- Article 11 – Freedom of expression and information.
- Article 17 – Right to property – property refers to possessions, and not just land and/or housing. This includes intellectual property.

### Equality

- Article 20 – Equality before the law.
- Article 21 – Non-discrimination – forbids discrimination on grounds of sex, race, colour, ethnic or social origin, genetic features, language, religion or other belief, political opinion, membership of a national minority, property, birth, disability, age or sexual orientation.
- Article 25 – The rights of the elderly – to live a life of dignity and to participate in social and cultural life.
- Article 26 – Integration of persons with disabilities.
- Solidarity
- Article 34 – Social security and social assistance.
- Article 35 – Health care - under the conditions established by national law.

### Citizens' rights

- Article 39: Right to vote and to stand as a candidate at [elections to the European Parliament](#).
- Article 40: Right to vote and to stand as a candidate at municipal elections – in Ireland, this means [local elections](#).
- Article 41: Right to good administration – this includes the right to have a say in any decision that would have a negative effect on you, the right to access your file, and the obligation for the State (or body making the decision) to give reasons for its decisions. For the EU institutions, this means that it should respond to citizen's requests in the language of the citizen.

- Article 42: Right of access to document.
- Article 43: Ombudsman.
- Article 45: [Freedom of movement](#) and of residence.

### Justice

Article 47: Right to an effective remedy and to a fair trial – this includes a [right to legal aid](#) where you are deemed to lack sufficient resources.

## 4.3. Convention of 13 January 2000 on the International Protection of Adults

The Convention of 13 January 2000 on the International Protection of Adults (HCCH 2000 Protection of Adults Convention) seeks to protect adults who lack capacity who are unable to protect their own interests. It does so by avoiding conflicts between the legal systems of Contracting Parties in respect of jurisdiction, applicable law, recognition and enforcement of measures for the protection of adults, including those relating to “powers of representation” (such as powers of attorney, guardianship etc.). The Convention ensures that these “powers of representation” have effect in another Contracting Party.

There are currently 15 Contracting Parties to the Convention, 12 of which are EU Member States. The full list of countries is: Austria, Belgium, Cyprus, Czech Republic, Estonia, Finland, France, Germany, Greece, Ireland, Italy<sup>1</sup>, Latvia, Luxembourg, Malta, Monaco, Netherlands, Poland, Portugal, Switzerland and United Kingdom (Scotland only).

The Convention affirms that the interests of the adult and respect for their dignity and autonomy are to be primary considerations. The Convention predates the UNCRPD, however, there is evident overlap with Article 12 on equal recognition before the law and Article 32 on international co-operation, for which the 2000 Convention establishes a system of Central Authorities.

Additionally, it provides a non-exhaustive list of measures designed to protect the interest of the adult, including the designations and role of representatives, as well as the administration of the adult’s property and the establishment of protective measures for the adult concerned.

In addition, it provides rules to determine which authorities should undertake necessary protective measures. Generally, authorities of the adult’s habitual residence hold jurisdiction (Art. 5), however, concurrent but subsidiary jurisdiction applies to the State of which the adult is a nation (Art. 7). The Convention also recognises the jurisdiction of the authorities of the State where the adult owns property (Art. 9), as well as acknowledging the exceptional need for emergency or temporary protective measures with limited territorial effect (Arts 10 and 11). There is flexibility within the Convention, allowing authorities with primary jurisdiction to request authorities in other Contracting Parties to take protective measures (Art. 8).

Generally, in exercising jurisdiction under Convention, authorities are expected to apply their own laws (Art. 13). However, it is possible for the adult in question, within the power of representation, to designate the applicable law governing the relevant powers exercised by the representative (Art. 15). The adult may choose to designate the laws of:

- A State of which the adult is a national
- The State of former habitual residence
- A State where the adult’s property is located.

In doing so, the Convention ensures that a power of attorney or similar instrument is enforceable in another Contracting Party, even if an analogous institution is absent in that State’s domestic legislation. This ensures that arrangements previously made by an adult in relation to their affairs will have their wishes respected in other Contracting Parties.

Protective measures directed towards the person or property of an adult that are taken in one Contracting

1. Our member noted that Italy signed the Convention on 31 October 2008 but that the ratification and execution of the Convention and the adoption of the rules for the domestic legal system had not been adopted. During the two legislatures preceding the current one, two Bills were presented (n. 2797 in the Chamber of Deputies on 23 December 2014; n. 2331 in the Senate on 15 July 2021), both are stopped or have not progressed further during the current legislature.

Party will be recognised by operation of law in all other Contracting Parties. There are limited grounds on which recognition may be refused (Art. 22).

As part of the Convention, Contracting Parties must designate the Central Authority who will have responsibility for the duties imposed by the Convention, in particular, mutual assistance and effective communication between Contracting Parties (Art. 28).

#### 4.4. European strategic drivers

##### **European Strategy on the Rights of Persons with Disabilities 2021-2030**

Published on 2 March 2021, the European Commission's "Union of Equality: European Strategy on the Rights of Persons with Disabilities 2021-2030" (ESRPD) builds on the previous European Disability Strategy 2010-2020, seeking to improve the lives of people living with disabilities across a range of policy areas by ensuring their rights are upheld. In particular, the strategy references the Charter of Fundamental Rights (CFR), the European Pillar of Social Rights (EPSR) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

Within the strategy itself, there is limited reference to legal capacity (in relation to voting, employment and access to justice). There is no reference to substitute decision-making and the need to replace these approaches at a national level. Only in the case of access to justice does the document make reference to supported decision-making, with a recommendation to collect good practice examples. Whilst there some other reference related concepts, such as autonomy or making choices about one's own life (especially in the context of deinstitutionalisation), there is little within the document about the exercise of decision-making and/or legal capacity, with no initiatives about working to encourage Member States to address this issue. Similarly, there are limited references to other protections for legal capacity, for example, in relation to marriage or contractual capacity etc.

There are some references to the political participation and involvement of people with disabilities within

political systems (including those at an EU level), however, the automatic loss of voting in a number of Member States as a result of being deemed to lack capacity and/or being subject to guardianship, is not addressed within the strategy.

However, there is a commitment within the strategy to work with Member States "to implement the 2000 Hague Convention on the international protection of vulnerable adults in line with the UNCRPD". As part of this, it commits to a study on the protection of vulnerable adults in cross-border situations, in order to support its ratification by all Member States.

##### **European Commission proposal on cross-border protections and the Hague Convention**

Currently, there are no EU laws specifically addressing the protection of adults in cross-border situations. At the time of writing, the European Commission has published legislative proposals, which covers adults who require support to make decisions and to protect their own interests, through some form of supported or proxy decision-making.

The Commission notes that the context of increasing cross-border mobility in the EU, challenges were presented to individuals in situation relating to managing assets or real estate in another country, seeking medical care abroad or relocate to a different EU-country. In particular, the complex and conflicting laws of Member States was noted, as was the potential legal uncertainty and lengthy proceedings.

The legislative proposals have two components: a Regulation and a Council Decision.

The proposed Regulation aims to help establish key points such as which court has jurisdiction, the applicable legislation, the conditions under which a foreign measure or foreign powers of representation should be given effect and how authorities can cooperate. It also proposes a set of practical tools, such as:

- Facilitating digital communication.
- Introducing a European Certificate of Representation, which will make it easier for representatives to prove their powers in another Member State.

- Establishing interconnected registers that will provide information on the existence of protection in another Member State.
- Promoting closer cooperation among authorities.

The proposal for a Council Decision provides for a uniform legal framework for protecting adults involving non-EU countries. It obliges all Member States to become or remain parties to the 2000 Hague Protection of Adults Convention.

The European Commission has previously promoted the ratification of the 2000 Hague Protection of Adults Convention by all Member States, as it is generally considered as an efficient and flexible private international law instrument for establishing

jurisdiction where there may be conflicting or overlapping claims. As not all Member States have joined the Convention, the Commission proposes to make it mandatory that Member States join this Convention.

The two proposals will provide for the necessary uniform rules and address the current gaps and inconsistencies in the legal protection of adults in cross-border situations. They will apply only in cross-border cases and will not change Member States' national substantive laws concerning the protection of adults. This legislative package will not apply to Denmark that has an opt-out in relation to Justice and Home Affairs. Ireland will be able to decide whether to opt in.



## 5. National policies and strategies

Alzheimer Europe wished to determine strategic and policy positions of countries in relation to legal capacity and supported decision-making, examining specific dementia strategies or other policy documents (e.g. strategies for older people or people with disabilities, as well as any other policy documents with relevance to the subject). As such, we asked our members to outline what, if any, government policies were in place.

### 5.1. Dementia strategies

Not every country has a dementia strategy in place and of those countries which do, the focus is often primarily on health and care services and support, in addition to areas such as awareness raising, dementia inclusive communities and research.

As such, some strategies do not directly reference where social protection is referenced, it is usually in the broader definition of the term, enveloping health and social care services, as well as a broad range of welfare benefits, including earnings replacements benefits.

#### Austria

The coordination group of the Austrian Dementia Strategy has defined a work package in 2023 that will provide an overview of the existing legal regulations that exist for people with dementia, from an ethical point of view.

#### Belgium

In Flanders, the current Flemish Dementia Strategy (2021-2025) touches on the topic of supported decision-making in relation to advanced care planning, however, there are no dedicated actions which tailored to people with dementia and/or their caregivers.

The Flemish Alzheimer's League, is aiming to promote the topic and have it placed higher on the agenda based on information gathered from our respective working groups of people with dementia and caregivers during June/July 2023 (further information is available in the good practice examples in section 11).

#### Czech Republic

'Strategic objective 5' of the Czech National Action Plan for Alzheimer's disease and related diseases, "Protecting the Rights of People Living with Dementia", contains a number of action areas which relate to legal capacity:

##### 5.1. Protection of the elderly, validity of signed contracts, assessment of legal capacity

- 5.1.1 The institution of a previously expressed wish
- 5.1.2 Raise awareness of public guardianship and of existing information material on this subject for public and private guardians, for people living with dementia, for informal carers and the wider public
- 5.1.3 Ensuring systemic availability of public guardianship in municipalities.

Additional details are available at: <http://tinyurl.com/2apm7zxt>

#### Germany

Within the German national dementia strategy, under Field of Action 2 "Supporting people with dementia and their relatives", subsection 2.2 is dedicated to "Supporting people with dementia and their family care-givers in legal matters". Under this section, it is mentioned that people with dementia and their relatives should be better informed about the possibility of free legal advice in case of need, by lawyers on the basis of the Advice Assistance Act. In addition, it is noted that care counselling and legal counselling should be better networked, general practitioners should be more aware of the topic of "dementia and legal issues" and legal guardians should be better informed about dementia.

### Ireland

Ireland's National Dementia Strategy, refers to the Assisted Decision-Making (Capacity) Bill 2013 on pages 22 & 23:

- p.22 *“It is not appropriate simply to assume that people with dementia are unable to make their own decisions. The independence of individuals should be protected for as long as possible and, as far as possible, according to their will and preferences. It is intended that the Assisted Decision-Making (Capacity) Bill 2013, when enacted, will support and protect people with dementia who lack or will shortly lack capacity to make and communicate decisions.”*
- p.23 *“The Health Service Executive will promote an awareness of the Assisted Decision-Making (Capacity) (Bill), when enacted, to ensure that people with dementia are supported to participate in all decisions that affect them, according to their will and preference.”*

### Malta

One of the recommendations included in the Malta Dementia Strategy (2015-2023), mentions the need to work towards the development of advance care directives, in recommendation 4.4i, Page 61.

### Norway

In the Norwegian DemensPlan 2025, there is a general recommendation to create an enduring power of attorney (fremtidsfullmakt) in order to ensure that the person's wishes are taken into account to the greatest extent possible throughout the course of the illness.

Both in the current and in the previous dementia plan, efforts have been initiated to develop guidance related to assessments of decision-making capacity, enduring powers of attorney, and similar matters. The National Clinical Guideline for Dementia and the newly developed Dementia Guide also emphasise the importance of planning for the future, including enduring powers of attorney, wills and inheritances, social security benefits and other considerations.

### Spain

In Spain's National Action Plan on Alzheimer's 2019-2023, there are a number of references under Axis 3 “Rights, ethics and dignity of the person” which relate to legal capacity, autonomy and rights of the person with dementia and their carers, specifically:

- 3.1. *To improve society's knowledge and awareness of the role of caregivers in their condition as persons.*
- 3.3. *To ensure conditions for better knowledge, access and exercise of their rights by people with Alzheimer's disease and their family caregivers.*
- 3.4. *To promote the incorporation of ethics in the intervention of the professionals in the social and health resources and avoid situations of mistreatment or abandonment of people with Alzheimer's disease.*
- 3.5. *To promote the progressive elimination of restraints in the management of people with Alzheimer's disease.*
- 3.6. *To advance in better services, support and benefits (from the different systems and areas: social, health, labour, legal, tax, housing, etc.) for family members and caregivers of people with Alzheimer's disease, aimed at ensuring the maintenance of the person in his or her natural environment.*

### United Kingdom - Scotland

Scotland's fourth national dementia strategy (Dementia in Scotland: Everyone's Story) was launched in June 2023. It is a ten-year strategy. It does not refer to legal capacity or supported decision-making. It does refer to the recommendations of the Scottish Mental Health Law Review.

## 5.2. Other strategies, policy documents or relevant documents

### Austria

In Austria, the Bioethics Commission published in 2013 a recommendation in relation to the participation of people without capacity in research projects. In addition, there are various information brochures on topics such as health care proxy and adult representation.

## Belgium

Within the Alzheimer's Action Programme of the Walloon Public Services (Service Public de Wallonie), training for professionals in relation to decision-making and capacity is noted as a development need.

In addition, the matter is addressed in the Code of Medical Ethics 2018, which was developed by the Belgian Order of Physicians.

## Czech Republic

In the Czech National Plan to Promote Equal Opportunities for Persons with Disabilities 2021-2025, Goal 6.1 is to “ensure that persons with disabilities are supported in their legal action”. The plan is available at: <http://tinyurl.com/3nwdugdu>

Additionally, some municipalities have actions and development plans which address issues of capacity and decision-making, for example Prague's plan for the development of social services 2022-2024, under goal 14.5, state:

*Strengthening the component of professional social counselling focused on debt issues and foreclosures, for victims of discriminatory practices and victims of prejudicial violence, areas of self-advocacy, guardianship and support in legal proceedings, so that in cooperation with other social services it is possible to comprehensively address the adverse social situation of the client.*

It was noted by our member association that most of these programmes are carried out by NGOs who deliver counselling, courses for carers or professionals.

## Estonia

Estonia is making the first steps to create the basic principles of the supported decision system. Ministry of Social Affairs in Estonia intends to begin piloting decision support activities and is currently in the process of carrying out a study on the current situation. The development and testing of the concept will be carried out from the funds of the 2024 European Social Funds.

The need to move from the substituted judgement model towards supported decision-making model has been identified by the Chancellor of Justice and various advocacy organisations, including the Estonian Chamber of People with Disabilities. The topic has been discussed in various publications in the field: <http://tinyurl.com/u9yxbdsv>

The Estonian Chamber of People with Disabilities shadow report on the implementation of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) has previously drawn attention to the shortcomings of the substituted judgement model. Their recommendation is to establish pre-conditions (legislation, operational voluntary guidelines) for moving to a supported decision-making model.

## Finland

Muistiliitto, the Alzheimer Society of Finland, has its own publication on ‘Support for decision-making: <http://tinyurl.com/2yandsu8>

Additionally, the Finnish Association on Intellectual and Developmental Disabilities (Kehitysvammaliitto) has resources on supported decision-making on its website <http://tinyurl.com/yc83tknd> as does the online service on intellectual disabilities <http://tinyurl.com/3muyjde4>

## France

The National Plan for Palliative and End-of-Life Care 2021-2024 is running a working group on the development of systems and tools for the early appropriation (with the advance directives for example or the “future protection mandate”) of rights in this area for all citizens. France Alzheimer participates in this working group to assert the rights and needs of people living with dementia.

France Alzheimer has been involved in the update of a resource by the “Haute Autorité de Santé (HAS)” to update the official recommendation “Participation of protected persons in the implementation of legal protection measures”, in order to take into account changes introduced by several legal changes over the past decade. The framing note for the work is available on the HAS website: <http://tinyurl.com/hmh9ctwy>. The final note is scheduled for 2024.

The official governmental website has a number of resources in relation to the preservation of autonomy and planning for future decision-making: <http://tinyurl.com/4jhujzj>

France Alzheimer addresses different measures of legal protection and for people living with dementia and explains which tools are available to make choices right after a diagnosis: <http://tinyurl.com/sz4mmbxj>

The website of “France Tutelle” <http://tinyurl.com/bdht5bda> also contains information in relation to protection, including “Benchmarks for families before setting up legal protection for their vulnerable loved one”, as well as explaining legal capacity and how to react when a person can no longer exercise their rights.

### Germany

The ISL e.V. the German branch of the international organisation of people with disabilities, published a brochure “Supported Decision-Making, Lightweight and Well Done” which relates to Article 12 of the UNCRPD. The brochure was written by people with disabilities or impairments through workshops and editorial meetings. The brochure is aimed at people making a decision and their supporters: <http://tinyurl.com/2c9x7utm>

### Ireland

“The Model of Care for Dementia in Ireland” sets out a range of targets and practice recommendations to advance the treatment, care and support for people living with dementia in Ireland and was published on 31 May 2023. The model notes the importance of timely diagnosis and early intervention, as well as planning for future needs and decision-making processes.

Additionally, the model supports the involvement of the person with dementia in research. Furthermore, the Assisted Decision-Making (Capacity) Act 2015 is mentioned throughout each of the five sections of the report. The report is available at: <http://tinyurl.com/5ybky5ht>

The Assisted Decision-Making (Capacity) Act officially commenced on 26 April 2023. There are a considerable number of resources and information on the Decision Support System, including in relation to:

- Decision-Making Assistant agreement information
- Co-Decision-Making agreement information
- Decision-making representation order information
- Advanced Healthcare Directive information
- Enduring Power of Attorney information.

The full resources are available on:

<http://tinyurl.com/49ndrjjs>

### Malta

In the National Strategic Policy for Active Ageing (2023-2030), there is a mention (page 69) of the need to introduce legislation for advance directives via the expansion of the ‘durable power of attorney’ in the Civil Code of Malta, in order to ensure that it extends to health care decisions in cases of mental incapacity.

The Strategic Policy can be found at: <http://tinyurl.com/4awfnvay>

### Netherlands

In May 2019, the Dutch Health Council published a report “Good Representation” in which supported decision-making was discussed, however, the response of the Minister of Health, Welfare and Sport, dated August 17, 2021, supported decision-making was mentioned only once.

A research project is currently being conducted (STRIDE) by researchers from several universities, mainly VU University Amsterdam, and a number of stakeholders, including Alzheimer Nederland, to design and realise an improved legal landscape for vulnerable adults in the near future. The project aims to find the balance between autonomy and protection and has a strong focus on supported decision-making.

### Norway

There is an ongoing revision of the Norwegian Guardianship Act, which aims to clarify the rules regarding self-determination. A general guardianship is generally a voluntary arrangement and should be based on the individual’s desire for and expressed consent to assistance.



Currently the laws regulating the use of coercion in health care services:

- The Mental Health Care Act
- The Act on Patient and Service User Rights
- Chapter 4A (coercive measures in somatic healthcare for patients, such as those with dementia), Chapter 9 of the Health and Care Services Act, (use of coercion in the care of people with intellectual disabilities) and Chapter 10 (use of coercive measures in the care of patients with alcohol and drug dependencies).

Together they comprise extensive legislation making it necessary for patients and services users to obtain an overview of several different laws in order to determine their legal rights. A commission has proposed a common Act regulating coercion in health and care services where the aim is to limit the use of coercion and has an increased focus on preventing the use of coercion.

In its work, the commission has also assessed Norway's international obligations, including the UNCRPD and has considered the need for amendments to the regulations in order to meet these obligations.

### Poland

The Polish Civil Code (Dz.U./Journal of Laws 2022.1360) in Chapter 1 describes legal capacity and capacity to perform legal contracts. In the Civil Code there is no reference to supported decision-making.

The term "incapacity" can be found in several legal regulations: The Family and Care Act; The Code of Civil Procedure (Art. 544-560); Mental Health Protection Act; Private International Law; Identity Cards Act; Legal Costs in Civil Cases Act; Bankruptcy Law; Tax Statute; Common Courts System Law and other acts and laws in which there are references to incapacitated employees which have to get redundant in such cases (even in The Museum Law).

The Constitutional Tribunal (Court), on 28 June 2016, ruled that regulations which do not allow an incapacitated person to check if they have been justifiably placed in a care institution are unconstitutional. The Tribunal emphasised that a fully incapacitated person has the right to express

their will and wishes in matters concerning their lives, while courts and other public institution are obliged to hear the person and take their opinions into account. This confirms the fact that despite lack of capacity to perform legal contracts, the opinion of the fully incapacitated person cannot be ignored while taking decisions about a placement in a care home.

The Tribunal decided that the regulations in the Mental Health Protection Act concerning the placement of fully incapacitated persons by their family caregivers in care homes are unconstitutional. The regulations which the Tribunal was reviewing and analysing did not guarantee legal protection of incapacitated persons against wrong will of their legal guardians. The assumption that a legal guardian has always the good of the person they look after does not always have to be true. The decision marks a turn in the assessment of incapacitation practices in Poland.

A Resolution no. 27 of the Council of Ministers of February 2021 was published in The Monitor Polski (Official Journal), position no. 218, on the approval of a document Strategia na rzecz Osób z Niepełnosprawnościami 2021–2030 (Persons with Disabilities Strategy 2021-2030). According to the Strategy, the Ministry of Justice becomes a coordinator of activities leading to the replacement of incapacitation institutions and the implementation of a model of supported decision-making, by which every person is provided with an opportunity to make decisions concerning their own matters in the broadest scope as possible. When it is necessary, such a person will be granted adequate support in decision processes.

As a result, substitute decision-making will only be applied in case there is no chance to establish or understand the person's will/wishes. However, the decision-making will take a different legal form, to ensure transparency and efficiency of actions taken in such situations. The Ministry of Family and Social Policy, Ministry of Health, Home Office, Government Plenipotentiary for Persons with Disabilities and Government Plenipotentiary for Equal Treatment, Human Rights Commissioner (Ombudsman) and NGOs will cooperate on implementation of the project between 2021 and 2025.

Work on supported decision-making and the abolishment of the incapacitation procedure at the Ministry of Justice, according to the information published on its website, is currently at an “analytical and conceptual stage”.

### Portugal

The legal capacity and supported decision-making legal framework is not specific for people with disabilities, older people or any other group. It includes any adult who due to health, disabilities or behaviour issues is not able to exercise his/her rights personally fully or fulfil his/her duties.

Some institutions (Public Attorney Department, the Portuguese Bar Association) have been organising several training programmes mainly to legal professionals (lawyers, judges, and public attorneys) and published guidelines or prepared training sessions and videos:

- <http://tinyurl.com/8hwm32y5>
- <http://tinyurl.com/msuecb3s>
- <http://tinyurl.com/mr2xkcdp>
- <http://tinyurl.com/2s3eepx3>
- <http://tinyurl.com/3892undd>

### Spain

In Spain, Law 8/2021, <http://tinyurl.com/mws4sv9y>, reforms civil and procedural legislation to support people with disabilities in the exercise of their legal capacity. This law aims to ensure the rights and protection of people with disabilities in the legal field and is based on the UNCRPD, with the principles of equality and non-discrimination in all aspects of life, including the exercise of their legal capacity. The law introduces significant changes to the support system for people with disabilities in the legal field.

A key aspect of the legislation is the removal of judicial incapacitation and has been replaced by supports for people with disabilities. In addition, guardianship, extended or rehabilitated parental authority and prodigality has been removed.

In their place are applied other figures such as personal legal capacity, the support provided by reliable persons designated by people with disabilities, the safeguard and provisional safeguard exercised by persons and

which aims to protect the rights and interests of the person with disability, the judicial defender designated by a judge who will act on their behalf and ensure their rights in court proceedings.

### Switzerland

A national working group co-led by the Swiss Academy of Medical Sciences (SAMS) and the Federal Office of Public Health (FOPH) is currently working to establish Advance Care Planning in Switzerland and ensure that it is embedded in daily practice.

### United Kingdom – Scotland

The Scottish Government Programme for Government <http://tinyurl.com/24752u3v> commits to Establishing a new Mental Health and Capacity Reform Programme to begin the process of updating and modernising our mental health and capacity legislation to enhance the protection of people’s rights.

The Mental Welfare Commission for Scotland has produced a guide titled “Supported Decision-Making: Good Practice Guide 2021”: <http://tinyurl.com/4ad3e5x7>

## 5.3. Information and resources relating to cross-border protections

Alzheimer Europe specifically asked countries if they were aware of any resources or additional information relating to cross-border arrangements for people requiring legal supports or protection. In particular, we were hoping to identify resources, which would provide additional information relation to both the Hague Convention but also to cross-border arrangements for people subject to legal protections.

### Contracting Parties to the Hague Convention

The German Federal Justice Ministry has a range of information on international cross-border situations on its website, including on the Hague Convention. It explains the role and function of the Federal Office of Justice as the German central authority for the Convention, as well as providing information on relevant legislation and explanatory reports, the relevant courts dealing with these matters, amongst information: <http://tinyurl.com/5w5jdm64>

In Poland information on cross-border protection in respect of healthcare is available on the website of the Patient's Rights Commissioner: <http://tinyurl.com/yc4yeyjp>

In addition, the Human Rights Commissioner publishes his opinions and complaints concerning cross-border protection on the website <http://tinyurl.com/4sz3tatp>

The Portuguese government has information on its website relating to cross-border protection of adults, including the Hague Convention: <http://tinyurl.com/22h7zh9>. In addition to this information, the designated Central Authority publishes each year a report on its activities with respect to the Convention: <http://tinyurl.com/y54btv9r>

The Swiss Government includes an information online about the Hague Convention and cross-border protections, including the relevant Federal Laws, as well as contact points for individuals and organisations at the Federal and Cantonal levels: <http://tinyurl.com/yc5sn246>

Although not a Contracting Party to the Hague Convention, Ukraine shared that cross-border protection is overseen by the Ministry of Foreign Affairs, with information on legal assistance available at: <http://tinyurl.com/54jp3cb9>



## 6. Legal capacity in European legislation

Legal capacity is not a unitary concept and one can distinguish between different kinds of legal capacities, which apply to different activities of daily life. The following sections provide information on how legislation regulates the issue of legal capacity in relation to:

- Contractual capacity – the ability of a party to enter into a legally binding contract.
- Testamentary capacity – regarding the ability of a person to draw up a will and bequeath their belongings to another person.
- Criminal responsibility – the responsibility of a person after having committed an offence or crime.
- Civil responsibility/liability – the liability of a person and their family for material damage caused by them.
- Marriage – the capacity for a person to enter into marriage.
- The right to vote – the capacity to exercise the right to vote in elections.

### 6.1. Contractual capacity

#### **Austria**

Decision-making capacity is regulated by law with decision-making capacity presumed for all in all persons from the age of 18. In order to be considered capable of making decisions, a person must fully understand the context and consequences of their own actions, adapting their will and behaviour accordingly. If a person fails to do so, they are considered as being incapable of making decisions. Decision-making capacity is the prerequisite for legal capacities such as the capacity to act or legal capacity. Specifically, contractual capacity is regulated in the General Civil Code, requiring that a person has reached the age of majority and is capable of making decisions. If a person does not have the capacity to make decisions, e.g. due to a mental disability, a mental illness or a similar impairment, they do not have the capacity to contract. In such cases, legislation provides four options to support the person concerned: the health care proxy, elected adult representation, the statutory adult representation or the legal adult representation. Contractual competence requires ability to sign legal transactions (e.g. tenancy agreement). A person with a health care proxy or adult representation is not automatically considered to have limited capacity. However, contracts can only be concluded if the decision-making capacity is given. If the decision-making capacity is not given, the person representing must consent to a contract. It is important that affected

persons are granted as much autonomy as possible. The law states that affected persons can conclude transactions of daily life if they do not go beyond the person's living conditions, for example, shopping at the supermarket, repairing an everyday objects or everyday leisure activities. Legal transactions involving larger sums of money e.g. the purchase of a car or a house, are not included.

#### **Belgium**

Article 492/1 of the Civil Code explains the procedures for incapacity in relation to contractual capacity in general. It is up to the Justice of the Peace to decide, on the basis of the person's state of health, whether or not the person is capable of entering into a contract.

#### **Bulgaria**

If the person is under full guardianship, he/she cannot conclude contracts. If a person with dementia is not under guardianship he/she can engage in contracts. In case of partial guardianship, the person can engage in contracts with the consent of his guardian. A contract which is signed by a person who cannot understand and guide his actions can be voided.

#### **Czech Republic**

There are three options/levels of adjustment of legal capacity, from support in decision-making to limitation of legal capacity with the appointment of a guardian.

## 1. Decision support

### Section 45 of Act No. 89/2012 Coll.

*If a person needs assistance in making decisions because a mental disorder makes, even though they may not be restricted in their legal capacity, they may arrange for the provision of support from a designated person or persons.*

### Section 46

- The supporter undertakes to the supported person that he will be present at their legal proceedings, providing them with the necessary information and communications, and to assist him with advice.*
- The agreement takes effect on the date on which it is approved by the court. If the contract is not in writing, the parties are required to commit to the contract before the court. The court will not approve the contract if there is a conflict of interest.*

### Section 47

- The supporter shall not jeopardise the interests of the supported person by undue influence or enrich himself unjustly at the expense of the supported person.*
- A supporter shall act in accordance with the decisions of the supported person in the performance of his or her duties. If the promoted person legally acts in in writing, the supporter may affix his or her signature indicating his or her position and, where appropriate, the support given to the supported.*

## 2. Representation by a household member

### Section 49 of Act No. 89/2012 Coll.

- If a mental disorder prevents an adult who has no other representative from acting independently, their descendant, ancestor, sibling, spouse or partners may represent them, so too may a person who lived in the same household for at least three years.*
- The representative shall give notice to the represented person that they will represent them and shall explain to them in clear terms the nature and consequences of the representation. If the person refuses, the representation shall not arise; the ability to express a wish is sufficient to refuse.*

Section 50 - Court approval is required for the representation to be established.

## 3. Guardianship

### Section 469 of Act No. 89/2012 Coll.

- The court shall, where a person's health causes them difficulties in the administration of their property or in the defence of their rights, appoint a guardian and, in accordance with such proposal, shall determine the scope of the guardian's powers. The court shall also, on the application of the person concerned, remove the guardian.*
- The guardian must, as a rule, act jointly with the concerned person; if the guardian acts alone, they must act in accordance with the will of the person. If the will of the person cannot be ascertained, the court shall decide on the guardian's motion.*

### Denmark

When a Danish citizen loses their capacity to act, reference is made to legal capacity and supported decision-making through the Act on Guardianship Act and Future Power of Attorney (referred to as Fremtidsfuldmagt). People with dementia have the right to make decision about their own lives and enter contracts if they are deemed to have capacity. Where the person does not have capacity, a guardian is appointed if there is no future power of attorney. This protects the person against abusive contracts.

### Estonia

Guardianship is established for a person who is unable to make decisions due to a mental health disorder.

#### By the Family Law Act:

*If a legal person becomes aware that it is possible to appoint a guardian who is a natural person to an adult, the legal person shall immediately notify a court and the rural municipality or city government thereof. A legal person shall verify at least once a year whether it is possible to appoint a guardian who is a natural person to a ward.*

*If a suitable legal person cannot be appointed as a guardian, the rural municipality or city government with which the adult is most closely connected shall be appointed as a guardian. An adult is most closely connected with the rural municipality or city government, inter alia, where the adult is from, where the adult has lived for most part of the time,*

*with which the adult has preserved essential ties, where the adult's close persons or assets are located or where the adult's residence according to the population register is.*

*Agreements related to the person under guardianship are concluded by the guardian to the extent that guardianship has been assigned to the person. As for transactions for which guardianship has not been set, the person does it himself. If it turns out after the transaction that a person with dementia participated in the transaction, who did not understand the content of the transaction at the time of the transaction, it is possible to reverse the transaction, through a request to the court.*

### **Finland**

A person with dementia does not automatically lose his or her legal capacity because of his or her diagnosis, but as the dementia progresses, it is necessary to assess what kind of matters the person is capable of deciding independently. The doctor will make the final assessment as to whether the person is legally capable of acting despite his or her dementia/memory impairment.

A guardian can be appointed to protect the interests of a person who is under a legal disability, even if the person objects. However, a declaration of incompetence is not made if other measures are sufficient to safeguard the person's interests. A guardian is only appointed if the person is unable to look after their interests or take care of matters concerning themselves or their property, and where these matters cannot be dealt with otherwise. A guardian cannot make a gift of their ward's property or perform any highly personal legal acts on their behalf, e.g. making a will. The guardian is appointed by a court or the National Board of Digital and Population Services.

### **France**

In principle, any adult person is designated as "capable" legally. This ability is associated with a presumption of "sanity". Incapacity prevents the person from exercising their rights alone and obliges them to be represented (by a parent, guardian or curator). Because of their vulnerability, the law has set up a system of protection according to the seriousness of the acts in question.

This is also the case for protected adults and in particular persons whose impairment prevents them from defending their interests. The law provides for the establishment of protection regimes for the conclusion of certain acts, in order to be assisted or represented. There are three regimes that the judge can choose according to the level of impairment: Safeguard of justice, curatorship or guardianship.

For an act to be declared valid and therefore non-cancellable, the person, in addition to having the capacity to conclude it, must have consented to it freely and in an informed manner. The act can be cancelled if it is proven that at the time of its signature, the person did not meet the aforementioned conditions, e.g. if the person's preferences and intent are hindered as a result of external actions (pressure, error, manipulation, violence). The law recognises preferences and intent as a valid where they are expressed freely, by a healthy mind and by a legally "capable" person.

### **Germany**

People with dementia can engage in contracts. If the person has a legal guardian or someone with a power of attorney, those persons can apply to have abusive contracts annulled.

### **Hungary**

In case of a limited capacity order, it is obligatory to define the line of case of which the limit is available. Additionally, the person has the right to make decision, though subject to the approval of the guardian.

The Civil Code (Act V of 2013) on the rules of capacity to act, guardianship and supported decision-making states that:

- 2:8. § (1) Every person has capacity to act until this capacity is restricted by this law or the verdict of court about incapacitation.
- 2:19. § [Limited capacity]

1. *Limited capacity has an adult person, who is placed under curatorship by the court during the terms of it.*
2. *The court places a person under curatorship with limited capacity, who has a great loss of ability of understanding – because of permanent or repeated appearance of mental disorder – and because of it the curatorship is justified in certain line.*

In relation to supported decision-making, the Civil Code states:

- 2:38. § [Appointment of a supporting person]
- 1. *The court of guardians makes a decision on the appointment of a supporting person if someone needs little help to arrange their affairs, or make decisions to avoid limiting their capacity.*

The court of guardians has a legal obligation to take care of this, with the decision-making itself falling under the court concerned.

### Ireland

People with dementia can enter contracts, as decisions relating to property and affairs can be supported under the 2015 Decision-Making (Capacity) Act. The Act can also support decision in terms of property, if one needs to buy, sell, or rent a house, how one spends money and pays bills and taxes, provides for others, applies for benefits, and other business and legal matters.

The Act puts in place three different types of decision supports depending on the level of support an individual needs to make certain decisions. A person can also plan for a time in the future when they might not be able to make certain decisions themselves. As part of the Act, the Decision Support Service (DSS) has been set up to support the introduction of these changes. The three types of support are:

- Decision-making assistant – a person makes their own decision with support from their assistant, who helps them to access and to understand information and to communicate their decision
- Co-decision-making agreement – the person makes specified decisions jointly with a co-decision-maker
- Decision-making representation order – the court appoints a decision-making representative to make certain decisions on the person's behalf.

Some people can get legal advice about the different decision support arrangements in Ireland from the Legal Aid Board. If someone makes an application to court about an individual's decision-making capacity, that individual can also get help from the Legal Aid Board.

### Italy

In relation to contractual capacity, the Civil Code (art. 1425) establishes that the contract can be cancelled if one of the parties was legally incapable. In addition, article 428 allows for actions to be annulled if performed by a person who, although not legally incapable, is in a state of incapacity to understand and want, where it results in serious prejudice for the person themselves. Finally, in the case of contracts, in addition to incapacity for the purpose of cancellation, bad faith of the contractor who took advantage of the other party's condition, must also be proven. In unilateral deeds, it is sufficient to prove the state of incapacity for annulment.

### Luxembourg

If no application for curatorship or guardianship is introduced for the person with dementia by the guardianship court, the person still can engage in contracts but is not protected from abusive contracts. There is no legal obligation for people with dementia to get curatorship or guardianship.

### Malta

Firstly, third parties (limited to those allowed to do by the Maltese Civil Code) may seek guardianship for an individual, and if deemed necessary, the individuals may also be deemed incapacitated by a court of law, at the request of the third party under article 189 of the Code.

Individuals under guardianship, interdiction or incapacitation may not engage in contracts. If they do, the law allows the possibility of challenging the legality of a contract entered into by such an individual, arguing for its nullity.

### Netherlands

People with dementia are not free to enter into a contract when an adult guardianship measure is applied, such as plenary guardianship (*curatele*) or financial guardianship (*beschermingsbewind*). Both measures not only lead to court-appointed representatives, but also limit the legal capacity of the person with dementia. With the consent of the guardian or sometimes the court, the person with dementia can enter into a contract.

The situation is different when applying the third guardianship measure, personal guardianship (*mentorschap*): this measure does not relate to financial interests, but only concerns care decisions. The legal capacity of a person under personal guardianship is limited only if this person does not have the mental capacity necessary to make the decision. The combination of financial guardianship and personal guardianship is almost equivalent to the protection of a plenary guardianship.

There are several forms of protection. With some contracts, every citizen has the right to dissolve the contract within a few weeks without giving any reason. A contract between a person under plenary guardianship or financial guardianship may be annulled on the grounds that the guardian has not consented. A third form of protection is the possibility of annulling any legal act on the grounds of mental incapacity or lack of decision-making skills. This is difficult to prove. It is even more difficult to terminate a contract on the basis of undue influence; the Dutch Civil Code contains a provision on undue influence, but there is a high burden of proof.

### North Macedonia

Due to lack of awareness, it is generally assumed that people living with dementia lose their capacity once diagnosed, and even earlier when they start showing some of the symptoms.

There is one legal process capacity assessment and assigning a power of attorney that applies to all decisions. The capacity assessment is carried out by two doctors, one of whom must be a mental health specialist, with a specific license. The psychiatrist then consults the court who makes the final decision, with

the outcomes of full or partial incapacity to make decisions. Legal capacity can be regained via the same procedure.

Members of the family of the person living with dementia, or social services, can suggest an initiation of both procedures. Once the person is assessed not to have capacity, social services take over the procedure of appointing a power of attorney. This is closer in nature to Guardianship, as the person living with dementia doesn't decide who becomes attorney. This is regulated by the Family Law and the Law for Nonmaterial Procedures. Attorneys then have the ability to make all financial, legal and medical decisions on behalf of the person living with dementia. The person with dementia is protected and supported by social services if necessary.

### Norway

People with dementia can generally engage in contracts provided that they have sufficient decision-making capacity at the time the contract is entered into. Decision-making capacity is assessed individually and can vary from person to person, depending on the stage of the disease and the specific situation. In Norway, there is a principle that individuals should have decision-making capacity, with emphasis placed on respecting the person's autonomy and right to make their own decisions. People with dementia who no longer have decision-making capacity can be appointed a public guardian, which is regulated in the Guardianship Act. An enduring power of attorney (*fremtidsfullmakt*) is a private law alternative which may also limit the possibility for people with dementia without decision-making capacity to engage in contracts. A guardianship may entail deprivation of legal/contractual capacity. Contracts entered into by people without legal/contractual capacity will be revoked.

### Poland

People with dementia have the same rights as other citizens until they become incapacitated by court. Like any other persons, mostly those with intellectual disabilities or unaware of dishonest practices, they may engage in contracts and sometimes be abused by unfair treatment. The Ministry of Family and Social Policy has published information on its website on



how to avoid engaging in abusive contracts, and what to do in case someone has been cheated. The Ministry has provided helplines and websites of institutions which one should contact when their consumer rights have been infringed.

### Portugal

In general, there is the presumption of capacity for individuals. If the person has diminished capacity, the “guardianship” court decision specifies the acts or category of acts that the person is able to practice by themselves and with or without assistance, including celebrating contracts. If the person enters into contract before any guardianship decision and in fact, has no capacity to do so, in such cases it must be proven that the person at the moment of contracting has no capacity. Otherwise, it would not be possible to revoke the contract based on incapacity. If a notary has doubts about the person’s capacity, they may refuse to make the deed or may ask for the presence of two doctors to certify the capacity of the individual.

### Spain

The new law (8/2021) reforms civil and procedural legislation to support people with disabilities in the exercise of their legal capacity and aims to protect people with disabilities from abusive or harmful contracts. To achieve this, the law incorporates several measures and safeguards including:

- Decision support system – The law establishes a decision support system for people with disabilities, including people with dementia, providing them with support to enable them to make decisions in autonomous and informed way. If a person with dementia can understand the terms and consequences of a contract with appropriate support, their participation in the decision-making process will be promoted.
- Involvement of reliable persons – In the support system, the involvement of reliable persons designated by the person with dementia is fostered. These persons can provide the necessary support to enable the person with dementia to express their will and fully understand the contract terms.
- Protection measures in cases of incapacity – When a person with dementia does not have the capacity to understand the terms of a contract, the

law contemplates the possibility of establishing protective measures, such as the figure of the legal defender. This defender will act on behalf of the person with dementia and will look after his or her rights and interests in the contractual process.

- Annulment of abusive contracts – The law establishes that if it is proven that one of the parties took advantage of the situation of vulnerability or incapacity of the person with dementia to enter into a harmful contract, such contract could be annulled by a judge.
- Adaptation of judicial procedures – The law also contemplates the adaptation of judicial procedures to ensure accessibility and effective participation of persons with dementia in procedures related to contracts and other legal matters.

### Sweden

A person can enter a legally binding contract as long as they understand the legal implications of the contract. It is not enough to show a person has dementia to make a contract void, it must be demonstrated they have been under the influence of a condition that made them unable to understand the legal implications of the contract. People with dementia can give enduring power of attorney to close relatives while their cognitive abilities still permit them to understand the consequences of such an action. If a person hasn’t specified who shall be given enduring power of attorney when they no longer can handle their own personal matters, a court can appoint a legal guardian and also limit the person’s ability to enter legally binding contracts on their own.

### Switzerland

Legal transactions require the capacity of judgement and the age of majority. According to Swiss law, capacity of judgement is assumed unless the opposite is proven.

Capacity of judgement must always be assessed in relation to a given situation (not only based on a general evaluation or diagnosis). This rule applies to financial/administrative matters as well as to medical decisions. In the later stages of dementia, capacity of judgment is generally questioned. It is presumed that a person with severe dementia is no longer capable of legal transactions and must therefore prove the

contrary in the event of a dispute (reversal of the burden of proof). However, for moderate dementia, there is a grey area which, in the end, has to be settled by court.

### **Turkey**

People with dementia can take legal action through their guardians. The procedures they have carried out while they do not have a guardian are valid until it is proven that they have dementia at the time of the procedure, with transactions made (outside of guardianship arrangements) being invalid.

### **Ukraine**

Presumption of capability/capacity is standard, with people living with dementia retaining all rights without limitations, including the right to conclude contracts. Where the contract violates the rights of the person with dementia and has indications of abuse, a concerned party (a relative, a prosecutor etc.) has a right to go to court to nullify such contract. If the court reaches the conclusion that the contract was concluded with a person with dementia who did so without fully understanding, the court can decide to void such contract.

### **United Kingdom – Scotland**

In Scotland there is a common law presumption of capacity, therefore there is presumption in favour that a person with a diagnosis of dementia has full contractual capacity: i.e the ability to enter into legally binding contracts unless there is evidence of incapacity. In Scots Law there is a long-established principle that a person cannot enter into a legally binding contract if they do not have the capacity to understand the nature of the contractual obligations. In the case where a person does enter into a contract it may be possible to either make representation to the other party (e.g. a creditor) to have a contract annulled. However, ultimately that may be a decision for a court.

The definition of incapacity is contained in the Adults with Incapacity (Scotland) Act 2000. It defines incapacity as being when a person is incapable of acting, or making decisions, or communicating decisions, or understanding decisions, or retaining memory of their decisions. Crucially capacity/incapacity are not all or nothing concepts. Incapacity should be considered

as decision specific. No one should be considered to have incapacity for making a decision(s) on the basis of being unable to communicate if that difficulty in communication can be overcome by any other means, including use of technology, human, or interpretative.

## **6.2. Testamentary capacity**

### **Austria**

The establishment of a last will or the appointment of an heir can only be done in person. The last will and testament must be definitive and free from threats or errors. The prerequisite for making a last will and testament is the so-called “testamentary capacity”. A person has the capacity to make a will if they understand the meaning and consequences of the last will and can act accordingly. The requirements for the last will are regulated in the General Civil Code. In the context of dementia, of particular importance is a certain paragraph therein, which considers a declaration of last will and testament to be invalid due to lack of testamentary capacity if the person was under the influence of a mental illness or intoxicated at the time of making it.

### **Belgium**

When the person is at an advanced stage of illness, article 901 of the Civil Code stipulates that the person must be fully conscious and of sound mind at the time the will is drawn up. It is up to the plaintiff to prove that the person making the will is no longer of sound mind.

### **Bulgaria**

People with dementia may make a will if they are not under guardianship. If they are under guardianship they cannot make a will.

### **Czech Republic**

The issues surrounding the last will and testament are dealt with in notarial proceedings and another party may challenge the will on the basis of the diagnosis (if any). The court must then decide whether the will is invalid.

Preliminary declarations may be helpful for people with early stages of dementia and their families.

The declaration is regulated in section 38 of the Civil Code, which states that: “In anticipation of his own incapacity to act, a person may express his will that his affairs be administered in a certain way, or that they be administered by a certain person, or that a certain person become his guardian.”

Three types of advance declarations can be inferred from this brief provision: The manner in which the affairs of the grantor are to be administered; the designation of a person to administer the grantor’s affairs, and the designation of a person to become the grantor’s guardian. The preliminary declaration may be a combination of some or all of these aspects.

### **Denmark**

People with dementia who lack incapacity may not make a will in Denmark. If a will is signed before a notary, it ensures that the person is impartial.

### **Estonia**

A person who is subject to guardianship cannot make a will, nor can a guardian make a will on behalf of the person under guardianship.

A patient will is a statement of what treatment a person wants or does not want in a situation where they are no longer able to make decisions themselves. Although patient wills are not common in Estonia, Estonian law also allows their use. An application for their use must be made whilst the person is still able to act, with a notary formalising future-oriented orders for the provision of medical services or property maintenance, for situations where the person themselves are not capable of making a decision not capable of decision.

### **Finland**

If a person with legal capacity and of legal age is not capable to take care one’s financial matters because of an illness, disability or other reason, one’s legal capacity may be restricted. A will is a legal act, that requires legal capacity, but general legal capacity does not necessarily cover testamentary capacity. For example, a person may be capable to make a simple contract or trade or even a simple will but not have legal capacity to more complex situations.

If a person’s legal capacity is in question, broad neuropsychological assessment should be carried out. Legal capacity has to be assessed in relation to every single situation, task and to a person’s medical condition. For example, guardianship does not automatically mean the loss of testamentary capacity.

Finland has no standard procedure to assess the capacity of people with dementia to make a will. An attorney or court of law may request a medical report in order to determine an individual’s testamentary capacity. These are likely to include an interview, observation and standardised tests. Testamentary capacity may be assessed after death, if it is suspected that person’s capacity to make a will was not sufficient and/or they were under pressure or undue influence.

### **France**

Where the person has reduced capacity, there is a distinction between curatorship and guardianship, with different implications for the creation of a will.

Curatorship consists in continuously assisting the person during the conclusion of certain acts. The person placed under this regime can carry out alone, without assistance, all protective and administrative acts. However, for acts of disposal, the curator must be present, without acting in place of the person. A will is a deed of disposition, however as it is deemed a personal act, assistance is optional. The law does not mandate that the will of an adult under curatorship be subject to the compulsory assistance of the curator. As such, the person under curatorship can draw up a will alone according to the formal conditions provided for by law, however, they can also be assisted if they wish. However, the validity of the will may be subsequently challenged. All acts requiring the presence of the curator, performed without them, will be cancelled.

Where a person is subject to guardianship, it is for the judge to determine, on a case-by-case basis, the acts that the person can perform alone.

The new law of 2007, which entered into force on January 1, 2009, abolished the assistance of the guardian in the drafting of wills by the person under guardianship. Since then, the adults under guardianship can only make a will if they have received

authorisation from the Family Council. However, the person under guardianship may revoke a will, without obtaining authorisation from the Family Council.

The Family Council makes its decision without establishing a medical opinion concerning the lucidity of a person. The condition of expression of a free and informed will remains despite the protection system and must be demonstrated in the event of a challenge to the will, and on the day of its drafting. Therefore, when the provisions contained in the will seem to have been taken at a time when the person under guardianship lacked discernment, they may be cancelled.

The judge determines, in the event of an application for cancellation, whether the person was in full possession of his mental faculties or not with the help, if necessary, of testimony, opinions and examinations. The will written before the placement under guardianship or curatorship may be cancelled if it is proven that the element which caused the placement of the person under protection existed at the time of writing.

A period of two years preceding the placement under protection of the adult covers the any obligations agreed to by the person during this period. Therefore, a will made during this time can be cancelled if there is evidence of the alteration of the mental faculties of the person and of a prejudice experienced by them.

### **Germany**

People with dementia can make a will as long as they have the capacity to do so, meaning they must be able to understand that they are making a will and what the content of the dispositions contained therein. They must also be able to determine the content of the will on their own initiative and to form a clear judgment on the scope of their instructions on the basis of their own reflection. This requires them to be aware of the reasons speaking for and against the instructions and to be able to weigh them up against each other. When drawing up the will, it must therefore be possible for the person to remember facts and events, information, grasp contexts and weigh them up against each other. In the event of a legal dispute, the person who doubts the testamentary capacity has the burden of proving

that the person was incapable of making a will. They must prove that the testator was no longer in full possession of their mental and psychological faculties when they signed the will. For proof of testamentary incapacity, a court-appointed expert will evaluate all the available information (medical documents, but also statements from friends and family members).

### **Hungary**

A person has the possibility to make preliminary declaration with legal effect under the Civil Code section 2:39. The preliminary declaration has to be registered to have it official recognised.

A guardian has the right to make decisions in the name of the person, manage finances and wealth to serve the interests of the person. A guardian has to account for these financial dealings and his activities to the court of guardians.

### **Ireland**

The Assisted Decision-Making (Capacity) Act 2015 does not cover decisions about making a will – this would be an issue for the Courts to decide.

As regards to making a will for someone living with dementia in Ireland, professional legal advice is required. The solicitor must be satisfied that the person understands what they are doing and the effect it will have and is not under undue pressure from anyone else.

In Ireland, to make a will, a person must be deemed to “have capacity”, that is, they are considered capable of making decisions about their financial and legal affairs. For this reason, a person with dementia who wish to make a will or change their will should seek legal advice from a solicitor as soon as possible after a diagnosis, while they still have decision-making capacity.

### **Italy**

A person without the capacity to act cannot make a will. More precisely, an interdicted person cannot make a will, whereas, a person subject to “amministrazione di sostegno” (support administration) measure, which normally does not deprive the subject of the ability to act, will require a judge to evaluate on case-by-case

basis. Since the will in the legal system is a personal deed, it cannot be drawn up by anyone other than the person concerned.

Finally, for people with natural incapacity (very old or with cognitive impairment) but who are not subject to any protective measures, doubts can arise as to whether or not they can make a will. There are two ways to approach making a will: a “public” will received from a notary and a “holographic” will. In the first case, the testamentary capacity of the subject will be assessed directly by the notary who can only receive deeds from persons capable of self-determination and therefore verifies that the person is incapable. In the second case, even an “incapable” person could create such a will, as the validity requirements require only that the will be written in the testator’s hand with the date and signature. In the latter case, the heirs may decide to challenge its validity, however, must prove the incapacity of the testator at the time of its drafting.

### **Luxembourg**

When the guardianship court has pronounced a curatorship for the person with dementia, the person maintains his testamentary capacity. In case of a pronounced guardianship, the person with dementia loses his testamentary capacity.

### **Malta**

People living with dementia may not make a will, as a result of articles 596 and 597 of the Civil Code. If substantial evidence is brought before a court that demonstrates that a person already living with dementia made a will, it may be challenged in court and may be deemed to be null. The previous will (prior to being medically diagnosed with dementia) will be put into place, and if no such previous will was made, the person living with dementia would be deemed to have passed away intestate. In this case, succession will take effect in terms of the law.

### **Netherlands**

People with dementia can make or change a will as long as they are mentally capable of doing so. It is up to the notary to assess the mental capacity of the person with dementia, which is sometimes difficult. There is a protocol to assist the notaries in assessing

mental capacity and if necessary they can ask a medical expert to do the assessment for them. In case of incapacity plenary guardianship approval from the court is needed to make or change a will.

### **North Macedonia**

A person deemed not to have capacity can no longer make/amend a will or be a witness for another person’s will. If they lose capacity after they have left a will, it will still be valid.

### **Norway**

People with dementia have testamentary capacity depending on their decision-making capacity at the time the will is created. If the person lacks sufficient decision-making capacity due to dementia, they may have limited ability to create a legally binding will. It may be necessary to obtain a medical certificate confirming that the testator has sufficient cognitive function and understanding to create the will.

### **Poland**

A person who has been fully incapacitated has no civil rights in this regard. Their testamentary capacity is no longer valid, so if a person with dementia makes their last will, it may be treated as invalid or challenged in court.

### **Portugal**

According to article 173º, nº 1, c) and article 67º, nº 4 of the Code of Notary, the notary must refuse to perform the act (the will) if they have doubts about the integrity of the mental faculties of the person and may ask medical experts to certify the capacity of the person.

Additionally, it is possible to revoke a will if the person, at the point of creating a will, was incapable of understanding the meaning of his declaration or if, by any reason (even if not permanent), is not in the full exercise of his capacity. As such, the will made by a person considered incapable is null.

The person may be considered, by court (in the framework of a “guardianship” process), not capable, for instance of managing their property but still able to make a will.

**Spain**

Law 8/2021 addresses the issue of the possibility of making a will, recognising in article 665 the right of people with disabilities to make a will, as long as they meet the capacity requirements established in the legislation.

Article 663 states that *“the person who at the time of testate cannot conform or express his will not even with the aid of means or support for it” cannot make a will, whilst article 665 states that “the person with a disability will be able to grant a will when, in the opinion of the Notary, he/she can understand and manifest the scope of his/her provisions.”* The notary ensures that the grantor develops their own decision-making process by supporting their understanding and reasoning, facilitating (with the necessary adjustments), that they can express their will, wishes and preferences.

Article 695 of this law states that: *“the testator will express orally, in writing or by any technical, material or human means his last will to the Notary. Once the testator has written the testament according to it and with an expression of the place, year, month, day and hour of its concession and the testator has been advised of his to read it himself, the Notary will read it aloud so that the testator manifests whether he is in conformity with his will. If he was, it shall be signed on the spot by the testator who is able to do so and, in his case, by the witnesses and other persons who must be present. If the testator states that he does not know or cannot sign, one of the witnesses shall sign for him and at his request. When the testator has difficulty or impossibility to read the testament or to hear the reading of its contents, the Notary shall ensure, using the adequate technical, material, or human means, that the testator has understood the necessary information and explanations and that he knows the testament faithfully reflects his will.”*

**Sweden**

A person can write a will as long as they are deemed to still understand the legal implications of the document. The will must be signed by witnesses that can confirm that the person signing the will have understood the implications of the document they are signing. A legal guardian or close relative with power of attorney cannot write a will.

**Switzerland**

As with contractual capacity, if a person is incapable of judgement, they cannot make a will. The heirs can appeal to the civil court if they have doubts about the capacity of judgement of the person who made the will.

**Turkey**

People with dementia cannot make wills.

**Ukraine**

People with dementia can make a will, which must be notarised. Before doing so, a notary public is obligated to convey to the person making the will consequences of it and make sure that the person has full understanding of his or her actions. If a notary public has any doubts, he or she can refer the person to the doctor to get an appropriate certificate. Also, if the notary has doubts, he or she can contact protective services in the place of the person’s residence.

Law of Ukraine “On Notaries” art. 44 states that if the need arises, the notary is to be presented with a certificate that states that the person does not suffer from a mental disorder that can influence his or her capacity to understand and (or) control one’s actions.

In case when the notary is unsure about the extent of a legal capacity of a natural person who requested notarisation, they should contact protective services in the place of the person’s residence to establish whether this person is under the guardianship or custody.

But even after that, the will can be nullified by the court decision if it’s discovered that the person has signed the will in a state where he or she didn’t understand the meaning of such action.

**United Kingdom – Scotland**

In Scotland a person must be of age and have testamentary capacity to make a will. As set out in the Age of Legal Capacity (Scotland) Act 1991, the age testamentary capacity in Scotland is 12 years. There is common law presumption in favour of capacity in Scotland. Therefore, a diagnosis of dementia in itself does not preclude a person from making or amending a will, only evidence of incapacity in relation

to understanding consequences of the decisions they make in the provisions of the will. This includes understanding the extent of the estate (finances & property) they are disposing in the provisions of the will.

As described in other responses The Adults with Incapacity (Scotland) Act 2000 also provides a test for testamentary capacity.

### 6.3. Criminal responsibility

#### **Austria**

A person is considered not legally sane if, at the time of committing the act, they were mentally ill, mentally disabled, impaired by a profound disorder of consciousness or incapable of seeing the wrongfulness of the act due to a severe mental disorder. In this case, the person is deemed not to be culpable due to insanity.

#### **Belgium**

Article 5 of the Penal Code stipulates that: *“Every legal entity is criminally liable for offences which are intrinsically linked to the achievement of its object or the defence of its interests, or for those which the concrete facts demonstrate have been committed on its behalf. (...) The criminal liability of legal entities does not exclude that of natural persons who have committed or participated in the same acts”.*

#### **Bulgaria**

People with dementia which are under guardianship are not responsible for criminal actions because they cannot understand and control their actions.

#### **Czech Republic**

Section 26 of Act No. 40/2009, Criminal Code states: *“Whoever, because of a mental disorder at the time of the commission of the act, could not recognize its wrongfulness or control his actions, is not criminally responsible for that act.”* As such, the psychological and the biological criteria must be cumulatively fulfilled for insanity to be established.

The biological criterion of insanity is based on a mental disorder under section 123 of the Criminal

Code 40/2009 which states: *“Mental disorder means, in addition to mental disorder resulting from mental illness, a profound disturbance of consciousness, mental retardation, severe antisocial personality disorder or other severe mental or sexual deviation.”* The Commentary to the Penal Code explains in more detail that the mental disorder which causes insanity may be transient and short-lived, ranging from a few seconds, to a few minutes or may be of a more prolonged or permanent nature

#### **Denmark**

People with dementia can be held liable for offences under the Criminal Code, which is the law dealing with criminal matters. The law covers a wide range of offences, including both minor crimes, which are punishable by a fine, and major crimes, which are punishable by up to several years in prison.

#### **Estonia**

Criminal responsibility is limited depending on the state of person`s mental health and they may not be punished for their actions. In more severe cases, involuntary emergency psychiatric care and placing adults in social welfare institution on basis of court ruling may be prescribed.

#### **Finland**

Under the Criminal Code, the perpetrator has no criminal capacity if, at the time of the act, due to a mental illness, a severe mental deficiency, a serious mental disturbance or a serious disturbance of consciousness, they are not able to understand the factual nature or unlawfulness of their act or if the person`s ability to control his or her behaviour is decisively weakened for such a reason (criminal incapacity).

#### **France**

A protected adult remains criminally liable. However, and contrary to the civil liability of the protected adult, the level of criminal responsibility of a protected adult is likely to be reduced by the magistrates (depending on the nature of the facts and their context).

The judges can indeed take into consideration the psychic or neuropsychic disorders of the person at the time of the facts, line with article 122-1 of the Penal

Code. An approved doctor, registered on the list of the public prosecutor, will have to indicate whether or not the protected person was aware of committing an offense or a crime for the facts of which they are accused.

The 2007 law granted protected adults a special criminal status, by including specific rules of procedure, defined in articles 706-112 to 706-118 of the Code of Criminal Procedure:

- A medical expertise must be carried out by a medical specialist before any judgment on the merits. This expertise is mandatory
- A protected adult who commits an offense must be assisted by a lawyer (except for minor offences)
- The curator or guardian must be systematically informed of the proceedings initiated against the protected adult
- In the event of a provisional incarceration, a visit permit is granted to them as of right
- For the hearing before the court, the curator or guardian may be summoned (failing this, their presence is strongly recommended). They are then heard as witnesses.

### Germany

Section 827 of the German civil code applies, which relates to exclusion and reduction of responsibility. A person who, in a state of unconsciousness or in a state of pathological mental disturbance precluding free exercise of will, inflicts damage on another person is not responsible for such damage.

### Hungary

In the Criminal Code of 2012, a person who does not have the capability to understand the consequences of their action(s) cannot be penalised. Additionally, a penalty can be reduced if the perpetrator is unable to realise the gravity of their action(s).

### Ireland

The Criminal Law (Insanity) Act 2006 relates to the trial and detention of persons living with mental disorders who are charged with offences and found not guilty by reason of insanity.

### Italy

The Code of Criminal procedure establishes that if the irreversible procedural incapacity of the accused is ascertained, and therefore their inability to correctly exercise rights and faculties within the proceeding, the judge is required to pronounce a sentence not to proceed. The procedural incapacity pertains to the total mental defect, capable of preventing the conscious participation of the accused in the trial, not revealing the partial incapacity.

For example, the fact that the accused is subjected to the measure of the “amministrazione di sostegno” (support administration) does not automatically determine the capacity of a person to take part in proceedings – this must be autonomously determined by the judge.

### Luxembourg

The law provides that in order to make a valid act, one must be of sound mind. In order to invoke nullity, the existence of a mental disorder at the time of the act must be proved. A person who has caused harm to another while under the influence of a mental disorder is nevertheless obliged to make reparation.

### Malta

Criminal culpability depends on whether the accused individual was already living with dementia when the crime was committed, since in order for an individual to be found guilty, it must be proven that both the act and intention to act were present.

If an act was committed by someone who is living with dementia, doubt arises as to whether that individual is capable of having a fair trial because they cannot testify to their version of events. Thus, if a psychiatrist examines the accused person and provides testimony that the person’s memory is not intact, the person cannot stand trial as they are not mentally fit for their rights to be exercised without any doubt.

The court here would also take into consideration whether there was the contribution of any third parties, for example, the person having charge of the person living with dementia having been negligent and that negligence contributing to the criminal offence having been committed.



### Netherlands

The Dutch legal system does not have separate rules for criminal offenses committed by older people. In the case of dementia, the person can be declared mentally ill, which can lead to no conviction and no criminal sanction, but also to a measure aimed at treatment (terbeschikkingstelling van de regering), although this measure is more commonly applied to violent criminals with a mental disorder.

### North Macedonia

People assessed not to have capacity can't initiate legal proceedings on their own – this must be done on their behalf by their guardian. The guardian also represents the person in court. According to the Law for Criminal procedure, if a person deemed not to have legal capacity has committed a crime, every case is considered individually, but generally, a person who is deemed unable to understand or control their actions, cannot be punished by law. In this case, alternative measures are put in place, such as other form of institutionalisation (e.g. at a psychiatric ward).

### Norway

Generally, if a person with dementia commits a criminal act, the question of their criminal responsibility will be assessed on an individual basis based on their ability to understand the unlawfulness of the act and their ability to act in accordance with this understanding. In Norway, the principle is that punishment is considered inappropriate and unacceptable if the person, at the time of the act, was psychotic, unconscious, in a severely impaired mental state, or otherwise unable to understand the unlawfulness of the act and to act in accordance with this understanding. There may be cases where a person with dementia is considered criminally irresponsible due to their inability to understand and control their actions.

The legal system recognises the need for appropriate measures and support for people with dementia, focusing on their healthcare needs and ensuring their well-being rather than applying punitive measures. In situations involving criminal acts by people with dementia, the emphasis would therefore be on providing appropriate care, treatment, and protective measures.

### Poland

An incapacitated person, like other people, has criminal responsibility for their actions, and may be charged for acting unlawfully. However, Article 31 § 1 of Criminal Code states *“it is not considered an offence or crime when committed by a person who because of having a mental disease, intellectual disorder or other mental disturbances, could not recognize the significance of his/her acts or control their behaviour while acting unlawfully”*.

In each case a court-appointed psychologist or psychiatrist has to examine the disorder/s present at the moment of committing the act. The expert's opinion will be the most important for the judge's decision and may influence the form of safeguard measures or punishment.

### Portugal

Article 20<sup>o</sup> of the Penal Code (*“imputabilidade em razão de anomalia psíquica”*) refers to the person that, due a severe mental disease, is incapable at the moment they commit a crime of assessing that it is illicit or is unable to acting accordingly with that assessment. Such a person will not be punished with a criminal penalty but a security measure (*medida de segurança*) may be applied (e.g. being hospitalised) if there is a serious risk of committing similar criminal acts.

### Spain

Article 20 of the Penal Code states that individuals *“Are exempt, at the time of committing the criminal offense due to any anomaly or psychic alteration, cannot understand the illegality of the act or act in accordance with that understanding, are exempt from criminal responsibility”*.

Criminal responsibility is dealt with consideration given to the mental capacity of a person at the time of committing a crime. A person is considered criminally responsible for their acts if they have sufficient mental capacity to understand the nature and consequences of their actions and if they can act in accordance with that understanding.

The main aspect in law address in relation to incapacity and criminal responsibility is the principle of culpability. To be considered guilty, the person is required to have mental capacity to understand what they are doing and to understand that their conduct is illegal. Exclusion from imputability due to mental illness means that a person cannot be criminally guilty and penalty cannot be imposed. Alternatives to punitive measures may include internment in psychiatric institutions or internment to receive treatment. The evaluation to consider a person unimputable is done through a psychiatric and expert assessment.

### Sweden

Dementia can lead to a person being freed from responsibility for criminal acts if they are deemed to have lacked intent. It can also lead to more lenient sentencing if the person is convicted.

### Switzerland

A person without capacity of judgement cannot be held criminally liable, under article 19 of the Criminal Code in two circumstances:

- If the person concerned was unable at the time of the act to appreciate that it was wrong or to act in accordance with this appreciation of the act, they are not liable for a penalty
- If the person concerned was only partially able at the time of the act to appreciate that their act was wrong or to act in accordance with this appreciation of the act, the court shall reduce the sentence. However, in-patient therapeutic measures may be taken.

### Turkey

Criminal capacity of persons with dementia is either absent or punishment is reduced, depending on the disability level reported by the medical authority on the disease.

### Ukraine

If the crime was committed by a person with dementia, who was found lacking legal capacity by the court, such person cannot be held accountable under criminal law. As an alternative to punitive measures, a person may be referred for treatment in a specialised medical facility.

A person who was found to have a limited legal capacity can be held accountable under criminal law.

#### Article 19 of the Criminal Code of Ukraine states:

1. A person who was aware of and could control his/her acts (omissions) at the time of an offence shall be deemed criminally sane.
2. A person who at the time of a socially dangerous act, as prescribed by this Code, was in the state of insanity, that is he/she was not aware of or could not control his/her acts (omissions) due to chronic mental disease, or a temporary mental disorder, or feeble-mindedness, or any other morbid mental condition, shall not be criminally liable. Such person may be subjected to compulsory medical measures upon a court decision.
3. A person who committed a criminal offence in the state of sanity, but prior to the judgment lapsed into a mental disease which renders that person unaware of or unable to control his/her acts (omissions), shall not be criminally liable. Such person may be subjected to compulsory medical measures, and may be held criminally liable upon recovery.

#### Article 20 of the Criminal Code of Ukraine:

1. A person found partially insane by a court, that is a person who at the time of the criminal offence was not completely aware of and could not fully control his/her acts (omissions) because of his/her mental disorder, shall be criminally liable.
2. The partial insanity shall be taken into consideration by the court in the infliction of punishment and may warrant compulsory medical measures.

### United Kingdom – Scotland

If a person is believed to have committed a criminal offence they may be arrested and charged. In some circumstances the police or the Procurator Fiscal may decide that a person with dementia was not able to be held criminally responsible. However, the person may have to go to court.

Part 6 of the Criminal Procedures (Scotland) Act 1995 makes provisions for how a person who may have a mental disorder and is charged with a criminal offence. It also makes provisions for a special defence under section 51a: "A person is not criminally responsible for conduct constituting an offence, and is to be acquitted of

*the offence, if the person was at the time of the conduct unable by reason of mental disorder to appreciate the nature or wrongfulness of the conduct.*” This would require medical evidence to prove that the person meets this test.

Similarly, Sect 51b makes provisions for diminished responsibility in the case of someone who would be convicted of murder to be convicted of culpable homicide instead, if at the time of the act, the person was “*substantially impaired by reason of abnormality of the mind.*”

There may be criminal proceedings. These are the steps the police and courts take to decide if a person is guilty or not guilty.

The court can ask a doctor to examine the person to determine if they have a mental disorder and provide a report to the court to help the court decide how to dispose of the case including if the person needs treatment.

Part 6 of the Act also provides a complex range of options for a court to dealing with an accused or convicted person who may have dementia. These include Assessment Yes and Treatment orders.

## 6.4. Civil responsibility

### Austria

The prerequisite for a person’s capacity to act is that he or she is capable of making decisions. Capacity to act means that a person can acquire or enter into rights and obligations through his or her own actions. Special forms of the capacity to act are the capacity to contract, the capacity in tort, the capacity to make a will or the capacity to marry.

### Belgium

Article 1382 of the French Civil Code defines the concept of civil liability as follows: “Any act of man, which causes damage to another, obliges the person by whose fault it occurred, to repair it”.

### Bulgaria

A person who is unable to understand and guide his actions is not responsible for the damages they caused. The person who is obliged to supervise they are responsible for the damages. These are the guardians and trustees. They are obliged to exercise supervision over the persons under guardianship and that’s why they are responsible for the actions caused by these persons.

### Czech Republic

In the Civil Code n. 89/2012 Coll., damage caused by a person unable to assess the consequences of his acts is dealt with as follows:

#### Section 2920 [Recodification]

1. *A minor who has not yet acquired full legal capacity or a person who suffers from a mental disorder shall provide compensation for the damage caused if he was capable of controlling his behaviour and assessing its consequences; the victim is also entitled to compensation for damage if he did not defend himself against the tortfeasor because of being considerate to him.*
2. *If a minor who has not yet acquired full legal capacity or the person who suffers from a mental disorder was incapable of controlling his behaviour and assessing its consequences, the victim is entitled to compensation if it is fair with regard to the property situation of the tortfeasor and victim.*

#### Section 2921

1. *The person who has neglected to exercise proper supervision over a tortfeasor shall compensate the damage jointly and severally with the tortfeasor. If the tortfeasor does not have the duty to provide compensation for damage, the victim is compensated by the person who neglected to exercise supervision over the tortfeasor.*

### Denmark

People with dementia can be held liable under the Liability Act (Erstatningsansvarsloven – LBK No. 266 of 21/03/2014), which is a Danish law that regulates certain matters of liability, especially regarding the determination of the claim.

**Estonia**

Civil liability is partially shared between the guardian and the person who is under guardian. The welfare institution has also responsibility. The Law of Obligations Act, section 1052 states:

2. *A person shall not be liable for damage caused by himself or herself if he or she caused the damage in such a condition that he or she could not understand the meaning of or direct his or her actions. Temporary disorders caused by alcoholic beverages or narcotic or psychotropic substances shall be taken into consideration only in the case where the tortfeasor is in such a situation for a reason other than his or her own fault.*
3. *A person who, pursuant to subsections 1 or 2 of this section, is not liable for damage shall nevertheless be liable for damage caused by himself or herself if it would be unjustified with regard to the victim to release the person from liability considering the tortfeasor's age, state of development and mental state, the type of act, the financial situation of the persons concerned, including existing insurance or insurance which such persons could normally be presumed to have, and also other circumstances.*
5. *The curator of a person with restricted active legal capacity who has been placed under curatorship due to mental disability shall be liable for damage unlawfully caused by the person to another person, unless the curator proves that he or she has done everything which could be reasonably expected in order to prevent the ward from causing damage. In the relationship between a ward and the curator, the curator is presumed to be liable even if the ward himself or herself is liable for the causing of damage.*

**France**

A person placed under legal protection remains civilly and criminally liable. In civil matters, common law applies. The civil liability of the protected adult is identical to that of any person. However, the adult person protected, because of the alteration of their capacities, must benefit from their tutor or curator from the means necessary to obtain compensation for the damage suffered. If the protected adult has modest means, they can claim legal aid.

**Germany**

Section 827 of the German Civil Code applies, dealing with exclusion and reduction of responsibility. Where a person is in a state of unconsciousness or in a state of pathological mental disturbance precluding free exercise of will and inflicts damage on another person, they are not responsible for such damage.

**Hungary**

Section 2:21 of the Civil Code, deals with total limited capacity. In matters of civil liability where the person is deemed to lack capacity, the court places a person under curatorship with totally limited capacity (i.e. a total loss of ability to understanding) as a result of permanent or repeated appearance of mental disorder. This only applies where partial limited capacity is unsuitable.

**Ireland**

Decisions about participation in government, church, volunteering, and memberships of voluntary associations, etc. can be supported under the 2015 Decision-Making (Capacity) Act. As outlined above, the Act puts in place new types of support depending on how much help a person needs to make certain decisions: Decision-making assistant; Co-decision-making agreement; and a decision-making representation order. However, areas of civil responsibility that are not covered by the 2015 Act are: decisions about being a member of a jury; making a will; marriage, divorce, or separation; adoption; and guardianship.

**Italy**

People who did not have the capacity to understand at the time they committed the act are not held liable for the consequences of the act. For the purposes of liability, therefore, reference must be made to the effective capacity of the subject to understand the effects of their own acts. In these cases, there is a responsibility of those who were required to supervise the person.

**Luxembourg**

The person under guardianship does not lose his or her civil rights, but these are exercised on behalf of the guardian.

**Malta**

Article 1035 of the Civil Code states that persons with a mental disorder or other condition (this would also include dementia) who are incapable of managing their own affairs shall not be bound to make good the damage they have caused. Yet, the injured person may take action against the person having charge of the person with a mental disorder or other condition in terms of article 1034 of the Civil Code on the basis of failure to exercise due care in preventing the act.

Where the injured party cannot recover the damages from the other person (because of limited liability or lack of means), the court may order the damages wholly or in part from the property of the person with the mental disorder/other condition in terms of article 1036 of the Civil Code. This is subject to the court taking into consideration the circumstances of the case, the means of the injured party and the means of the party causing the damage.

**Netherlands**

According to Article 6:165 (1) of the Civil Code, the fact that the person with dementia acted under the influence of an intellectual defect does not exclude him from legal liability. In case of a plenary or personal guardianship, the guardian might be held liable on the grounds of insufficient supervision.

**Norway**

As with criminal capacity, civil responsibility will be individually assessed based on the person's decision-making capacity.

**Poland**

A fully incapacitated person loses the power to perform acts in law, such as signing contracts or entering into legal transactions but does not fully lose legal capacity. As with criminal responsibility, a person who has been incapacitated, may not be legally liable for their actions, if a court-appointed psychologist or psychiatrist proves that the person acted without being aware of the consequences.

**Portugal**

According to Articles 488° and 489° of the Civil Code, in principle, the person is not responsible for the damages that they caused if, at the moment of acting,

they were not capable of understanding. However, if the person(s) in charge of surveillance of the person are not able to support the damages, the incapable person may be responsible. In such cases, the incapable person may not be deprived of a minimum to satisfy her/his basic needs.

**Spain**

The exemption from criminal liability in Article 20 mentioned above does not include that of civil responsibility. The response to matters of civil liability will consider:

- Must be determined what is the patient's ability to understand the actions (acts, consequences... etc.)
- Different measures must be established by the relatives/companions to avoid situations of a similar nature (total or partial institutionalisation, treatment, close supervision of the family or companions...etc.)
- Tribunal court will decide the amount of compensation for damages for the patient, and the relatives/companions may respond in a subsidiary way for him.

**Sweden**

See above about criminal responsibility.

**Switzerland**

In principle, a person without capacity of judgement is not liable for any damage they cause. However, on grounds of equity, the court may order a person who lacks capacity to consent to provide total or partial compensation (e.g. if the person who suffered the damage is economically significantly less well off than the person who caused it).

**Ukraine**

In Ukraine, people with dementia can be held civilly responsible (if they haven't been recognised as lacking legal capacity by the court). If they have been recognised as lacking legal capacity by the court, their guardians will be held accountable.

**United Kingdom – Scotland**

A person with dementia has the same civil rights and responsibility as other citizens. As stated elsewhere in response to questions there is a common law

presumption of capacity in Scotland, therefore there is presumption in favour that person with a diagnosis of dementia has capacity unless there is evidence to the contrary. In respect of civil responsibility then a person with a diagnosis of dementia holds the same responsibility as any other person unless there is evidence that they do not have capacity in respect of specific civil responsibilities.

## 6.5. Marriage

### **Austria**

The Marriage Act stipulates that two persons can only enter into marriage if they are both capable of marrying at the time of marriage. In this context, marriageable means that one person is of age and capable of making decisions. If there is no decision-making capacity - for example in the case of severe dementia - a marriage that has taken place is to be considered null and void.

The Marriage Act in Austria also regulates under which circumstances a marriage can be divorced. Accordingly, it is possible to dissolve a marriage on the grounds of fault – e.g. marital misconduct - or on the grounds of conduct that is detrimental to the marriage without fault. One paragraph states that divorce is possible if the marriage is so broken due to mental illness or impairment that recovery is unlikely.

### **Belgium**

Article 491/1 of the Code defines the notions of capacity for marriage. When a person is unable to marry, it is up to the justice of the peace to decide, based on the person's state of health, what constitutes capacity and incapacity.

### **Bulgaria**

If a person is put under full guardianship, she/he cannot marry.

### **Czech Republic**

The prohibition to marry does not come automatically with the restriction of a person's legal capacity, as was previously the case with the deprivation of legal capacity. This prohibition would have to be expressly decided by the court in the context of a ruling on the

restriction of legal capacity. If a person were to marry regardless, the marriage would be declared null and void. However, if a child is conceived in such a marriage and is born alive, the marriage cannot be declared void, in the interests of family protection.

### **Denmark**

You are not allowed to marry in Denmark if you are deemed to lack capacity.

### **Estonia**

If a person has been granted guardianship, it is decided separately whether he is capable of marriage, regulated by the Family Law Act. An adult with restricted legal capacity may marry only if they sufficiently understand the legal consequences of marriage. If a guardian has been appointed, it is presumed that the person is unable to understand the legal consequences of marriage, unless otherwise provided in the ruling concerning the appointment of a guardian.

### **Finland**

A person with dementia does not automatically lose his or her legal capacity because of his or her diagnosis, but as the illness progresses, it is necessary to assess what kind of matters the person is capable of deciding independently. The doctor will make the final assessment as to whether the person is legally capable of acting despite his or her dementia/memory impairment.

### **France**

This is the French Civil Code which regulates the issue of "marriage" for people under legal protection. A law in 2019 abolished the request for authorisation from the protected person to the guardian or curator to marry. The protected person therefore no longer needs this authorisation to consider getting married but must inform the guardian or curator of his marriage plan.

This information is free in its form or content, but it must enable the curator or tutor to oppose it: the curator or tutor must know the identity and address of the future spouse, the date and place of the celebration of marriage. The future spouses must provide a document to the civil registrar at the town hall, proving that they have informed the curator or

guardian. The presence of the tutor or curator when filing the file is also possible as proof.

### Germany

If a person with dementia no longer has legal capacity, they may not marry. Legal guardians may not give proxy consent in this case.

### Hungary

If a person with no legal capacity makes a legal declaration, it is considered void except for everyday issues with no real consequences.

### Ireland

In Ireland, one must have the capacity to marry. That is, a person must freely consent to the marriage and have the capacity to understand what marriage means. A person cannot be forced to marry someone and must have the capacity to understand the nature of marriage. The Assisted Decision-Making (Capacity) Act 2015 does not cover decisions on marriage, divorce, or separation. This would be an issue for the Courts to decide.

### Italy

The Civil Code establishes certain conditions for being able to contract marriage, including one linked to age (reaching the age of 18) and one linked to mental capacity from which interdiction derives. For other “vulnerable” subjects, the same applies as for the will. A person subject to the protection measure of the “amministrazione di sostegno” (support administration) can contract marriage unless the Tutelary Judge has expressly provided for limiting this ability in order to protect the individual from abuse. Marriage is considered a personal act and therefore cannot be delegated, with the exception of the provisions of art. 111 of the Civil Code.

### Luxembourg

In case of curatorship (partial guardianship) the consent of the curator or the guardianship judge is needed for marriage. In case of guardianship an approval of a Family Council is needed for marriage and the opinion of the treating physician is sought. The Civil Code of Marriage provides, if one of the spouses is unable to express his or her will, the other may be authorised by the courts to represent him or

her, generally or for certain specific acts, in the exercise of the powers arising from the matrimonial regime. The conditions and extent of such representation are determined by the family court.

### Malta

Article 4 of the Marriage Act, states that a marriage contracted between persons either of whom is incapable of contracting by reason of infirmity of mind, whether they were interdicted by a court of law or not, shall be void.

### Netherlands

The civil registrar is required by article 1:32 of the Civil Code to check whether both parties have the required mental capacity when entering into a marriage. The explicit requirement in this article reads: “A marriage should not be entered into when the mental faculties of one party are so disturbed that he is unable to determine his will or understand the meaning of his statement.” In case of a plenary guardianship approval from the court is required.

### North Macedonia

People assessed as having full incapacity can't get married, while people assessed as having partial capacity can get married with the approval from the guardian (attorney).

### Norway

People with dementia have by default the right to marry, as the Norwegian Marriage Act does not impose specific limitations based on a person's health condition or diagnosis, including dementia. However, the Marriage Act requires both parties in a marriage to give valid consent to the marriage. Therefore, if a person lacks sufficient decision-making capacity due to dementia or other cognitive challenges to understand the significance of marriage or provide informed consent, they may be deemed lacking sufficient decision-making capacity. In such cases, the marriage typically would not be considered valid, unless specific legal measures have been taken to allow for the marriage, such as a guardian consenting to the marriage.

### Poland

A fully incapacitated person cannot get married.

**Portugal**

The rights to get married and to live in civil partnership are part of a broader right to citizenship previewed in article 26° of the Constitution. These rights are also previewed in article 67° of the Constitution, that the family, as a fundamental element of society, has the right to the protection of society and of the State to ensure the conditions to fulfil it.

The current legal framework regulating the legal capacity of everyone who is unable to fully exercise their rights is article 147° of the Civil Code on “personal rights and business of everyday life” that states that, the exercise of these rights is free unless the law or a court decision states differently. This means that, as a principle, these rights remain in the autonomy of the person. These personal rights include the right to marry, to live in a civil partnership, to procreate, to recognise someone as their child or to adopt, amongst others.

Regarding marriage, even in the absence of a court decision ruling on a person’s capacity, Article 1 601° b) of the Civil Code imposes this incapacity in case of “Demência notória” (when the person shows clear signs of dementia), even if there are moments of lucidity. This means that the person may see restriction on the exercise of some rights (managing property or business, making a will, etc.) but may preserve the right to get married or live in a civil partnership. However, the person may see the right to get married denied without a court decision.

**Spain**

Spanish legislation addresses incapacity in relation to marriage in a manner that it protects the rights and will of the people with disabilities. There is capacity to get married in Spain as long as they have the legal capacity to do so. This implies that both persons must have the mental capacity to understand the nature and the legal effects of marriage. In the case of one of the parties has a disability to understand marriage an evaluation of the capacity may be required. For this purpose, a judge or a notary may request a medical or psychological evaluation to determine whether a person has the necessary capacity to freely consent marriage, which must be celebrated freely, voluntarily and without deception.

In the case of one of the persons does not have the capacity to consent marriage due to a disability, the judge may establish protection measures such as legal representative or tutor who ensure his or her rights and interests. In the case that a marriage is found to have been contracted by one of the parties without capacity to consent or under compulsion, marriage may be declared null by a court.

**Sweden**

Legal guardians or close relatives with power of attorney cannot make decisions in personal matters such as marriage.

**Switzerland**

Marriage may be entered into by two persons who have reached 18 years of age and have capacity of judgement, according to Swiss Civil Code, art. 94. The legal representative acts for a person lacking capacity unless a right is so strictly personal (for example marriage) that any form of representation is excluded in line with Swiss Civil Code, art. 19c, para. 2.

**Turkey**

People with dementia can marry if the level of dementia has not eliminated the power of discernment; but if the power of reasoning has disappeared, they cannot marry. Marriages with people with dementia are not valid.

**Ukraine**

People with dementia can enter into marriage, however, the person should notify the other person entering into marriage about the state of their health. If the person with dementia has been found lacking legal capacity, he or she cannot get married, in line with the Family Code of Ukraine, art. 39 p. 3. Additionally, the Civil Procedure Code of Ukraine, art. 236-241 invalidates any marriage with a person who has been found lacking legal capacity, meaning by a court decision, before the registration of marriage.

**United Kingdom – Scotland**

A person with dementia has the same civil rights and responsibility as other citizens. As stated elsewhere in response to questions, there is a common law presumption of capacity in Scotland, therefore there is presumption in favour that person with a diagnosis



of dementia has capacity unless there is evidence to the contrary. In respect of civil responsibility then a person with a diagnosis of dementia holds the same responsibility as any other person unless there is evidence that they do not have capacity in respect of specific civil responsibilities.

A person can get married in Scotland if they are:

- Aged 16 or over
- In an opposite sex or same sex relationship
- Not married or in a civil partnership with someone else
- Not closely related
- Capable of understanding what marriage means and of consenting to marriage.

The definition of incapacity contained in the Adults with Incapacity (Scotland) Act 2000 is relevant.

There is a legal impediment where one or both of the parties is incapable of understanding the nature of the ceremony or of consenting to marriage/civil partnership (Marriage (Scotland) Act 1977 s5(4)(d); Civil Partnership Act 2004 s92(2))<sup>25</sup>. If there is an objection which brings into doubt a person's capacity to enter into marriage/civil partnership, medical evidence would be required in order for the objection to be upheld.

The General Register Office for Scotland, which deals with registration of births, deaths and marriages, is the sole determinant of whether someone is capable of entering into the marriage contract or a civil partnership.

There are some limited civil remedies to protect individuals who may have entered into a marriage or a civil partnership but lacked the capacity to do so.

The Mental Welfare Commission have produced a good practice guide "Consenting Adults: Capacity, rights and sexual relationships which covers marriage". <http://tinyurl.com/5hdcntvv>

The Forced Marriage Scotland Act 2011 also makes provision which can protect someone who may be about to be forced to marry or who are already in

a forced marriage. These include stopping a forced marriage from happening, or provide protective measures if the marriage has already taken place.

## 6.6. The right to vote

### Austria

In Austria, the active right to vote allows citizens from the age of 16 to exercise their right to vote. Passive suffrage is the right to stand as a candidate in an election. A person may be disqualified from both voting and standing for election under certain conditions, however, a dementia-related illness is not a reason for exclusion per se.

### Belgium

All eligible voters are entitled to vote. That is, to be 18 years of age, to be entered in the population and commune registers, and to enjoy civil and political rights. However, a Justice of the Peace may declare a person unable to vote.

### Bulgaria

People under guardianship do not have the right to vote. If a person with dementia is not under guardianship she/he can vote but without support when voting.

### Czech Republic

Before any restriction of legal capacity, the court must address the question of the exercise of constitutionally guaranteed rights and freedoms, including the right to vote. It must consider all the relevant facts and, where appropriate, make an express decision on the issue, i.e. the restriction of the right to vote must be stated directly in the operative part of the judgment.

### Denmark

People with dementia have the right to vote unless the person has been deprived of legal capacity. A person who has been completely deprived of legal capacity is incapacitated and thereby loses the right to vote in elections to the Folketing. The person can still vote in municipal, regional and EU elections. If the person needs help with the ballot paper or ticking their box, they can get help with it from two election officials or assigned voters.

**Estonia**

If a person is assigned to guardianship, a decision is also made on his right to vote. The right to vote is not automatically restricted.

Voting rights in connection with legal capacity is regulated by Code of Civil Procedure, which in cases when the court had appointed a legal guardian to execute all areas of life or the responsibilities of the legal guardian are enlarged to all areas, the person under guardianship loses the right to vote.

Whether the person under legal guardianship can vote or not depends on the scope of guardianship. Though Estonian case law has interpreted the voting rights and restrictions differently. In some civil law cases it has been stated that if the person can independently execute minor transactions, the person should be counted as able to vote, whilst other case law focusses on whether the person understands the meaning of elections or not. Even in cases where the right of executing minor transactions remains, voting rights are not guaranteed.

**Finland**

The right to vote is independent of the legal capacity of the adult. Thus, a person who is under guardianship under the Guardianship Act or a person who has been declared as lacking capacity has the right to vote in elections and to participate in referendums.

If the voter's ability to cast a ballot is substantially impaired, they may be assisted by an assistant. Under the electoral law, the assistant can be either an election official or a person chosen by the voter, such as a close relative. The assistant must not recommend to the voter which candidate the person should vote for.

**France**

The programming law for justice amended in 2019 reformed the electoral code and right to vote, for adults placed under guardianship. The latter can now exercise their right to vote under the same conditions as other protected adults (adults placed under curatorship, adults benefiting from personalised social support measures, legal support, family authorisation or the safeguard of righteousness).

In Section L64 (Modified by Law n°2019-222 of March 23, 2019 - art. 11) of the Electoral code:

*“Any voter suffering from definite infirmity and making it impossible for him to introduce his ballot in the envelope and to slip it into the ballot box or to operate the voting machine is authorized to be assisted by a voter, of their choice, other than one of the persons mentioned in 1° to 3° of Article L. 72-1, in the case of adults under guardianship.*

*When a voter is unable to sign, the signature provided for in the third paragraph of Article L. 62-1 is affixed by a voter of his choice who follows his signature with the following statement: “The voter cannot sign himself”. In accordance with Article 109 IV of Law No. 2019-222, these provisions apply to persons who benefit from a guardianship measure on the date of publication of this law as well as to the authorities in progress on the same date. The other provisions of the judgment pronouncing or renewing the guardianship measure continue to apply.”*

**Germany**

The right to vote is a personal and elementary civil right, which cannot be transferred to another person, nor can it be exercised by relatives, proxies or legal guardians, as per section 14, par. 4 of the Federal Election Law. As of 1 July 2019, people with dementia may no longer be excluded from exercising their right to vote and may be assisted to vote in the election, to fill in the ballot paper according to their wishes. Registration authorities must automatically reinstate people with dementia who have been removed from the electoral roll on the electoral roll.

Any form of influence or manipulation of the voting decision is forbidden and subject to punishment.

**Hungary**

As stated in the Fundamental Law, a person who is under guardianship has no right to vote.

**Ireland**

The presumption is that a person has capacity to vote unless the opposite is shown. If a person is registered to vote, the decision about whether they have capacity to vote on Election Day will fall to the Presiding Officer at the polling station. The Presiding Officer is the

person responsible for taking the poll at a polling station. If there is a dispute about whether a person has capacity to vote this will need to be decided by the courts.

If necessary, a person with dementia can ask to have their voting paper marked at the polling station by a companion or by the Presiding Officer, but the Presiding Officer can refuse to provide any assistance during the last two hours of polling. If a person wants a companion to assist them, they must be at least 16 years old and cannot be a candidate or an agent of a candidate.

### **Italy**

The right to vote is governed by art. 48 of the Italian Constitution. The right to vote is personal and cannot be expressed by proxy, with the only permitted exception being assisted voting. This applies to persons with physical or sensory issues (or other disability which requires assistance), who can be accompanied in the booth by another registered voter.

At the request of the interested party, the annotation of the right to assisted voting is inserted in the electoral card by affixing a symbol or code and upon presentation of a medical certificate certifying that the person requires support from another person to be able to vote.

Finally, with reference to people lacking capacity, it must be specified that the right to vote has been granted to them by art. 11 of Law no. 180 of 78, which repealed point 1), art. 2, of the Decree of the President of the Republic of 20 March 1967, which previously denied this right.

### **Luxembourg**

A new law came into force on 1 July 2023, guaranteeing adults under guardianship the possibility of exercising their right to vote and to stand as a candidate by right in all cases.

However, as voting is compulsory in the Grand Duchy of Luxembourg, in order to avoid the benefit thus created for adults under guardianship turning to their disadvantage in cases where the most vulnerable persons in question would not have the faculties

necessary to understand that their participation in the vote is compulsory, or even to express their right via postal voting or to be able to the polling day, adults under guardianship were added to the list of persons excused from voting. These legislative changes applied for the first time for the parliamentary elections in October 2023.

The legislative amendments also made provision for people under guardianship to be supported by another person when voting.

### **Malta**

People legally deemed to not have capacity cannot vote.

### **Netherlands**

People with dementia as well as persons under guardianship have the right to vote in elections. They may also grant a power of attorney to another person to cast the vote on their behalf. The guardian may only cast the vote of their client with a power of attorney.

Persons with a physical disability are entitled to support up to the voting booth, however, it is not available for people with a mental or intellectual disability. There is currently a proposal in which people with a non-physical disability should be entitled to support from an independent expert. To avoid undue influence, the representative of the person with mental or intellectual disability cannot be this support person.

### **North Macedonia**

People assessed not to have legal capacity can't vote in elections under any circumstances.

### **Norway**

People with dementia have the right to vote in elections, including if they are under legal guardianship. They also have a right to have a person of their choice assisting them in voting. People living in nursing homes or assisted living are able to vote in advance of the election day in their place of living.

### **Poland**

By virtue of the Polish Constitution, such persons who are deemed not to have capacity are deprived of the possibility to vote in any elections and the right to be

elected. Fully or partially incapacitated persons lose their voting rights, though people with dementia can vote if they are not incapacitated.

However, in 2019 elections a District Court in Nowy Sacz decided that it was unconstitutional to forbid a person who was partly incapacitated to vote. This was a precedent. The judge referred to ECHR and UNCRPD. The judge also highlighted the inconsistency in Polish law which allows incapacitated persons to become political party members, but takes away their voting rights.

### Portugal

A person can vote unless they show as having a severe mental function limitation (independently of, existing or not, a court decision on their capacity) and when the person lives in a psychiatric facility or if the severe mental function is assessed by a board of two doctors at the moment of voting. This happens according with specific legislation on the different election procedures (to municipalities, to the parliament or to the President of the Republic).

Recent court decisions decided that the “guardianship” court decision is not the appropriate place to decide if the person is capable or not to vote.

### Spain

According to Spanish legislation, people with dementia can vote as long as they meet the requirements established in the Constitution and the Organic Law of the General Electoral System (LOREG) which states that people must be over 18 years of age, registered in the electoral roll, and have Spanish citizenship.

The Organic Electoral Law was amended in 2018, allowing people with dementia to have the right to participate through universal suffrage and states:

- Any person may exercise his or her right to active vote, consciously, freely and voluntarily, whatever their form of communication is and with the means of support they may require.
- An eight additional disposition is added with the following wording: From the entry into force of the Law amending the Organic Law on the General Electoral System to adapt it to the International

*Convention on the Rights of Persons with Disabilities, the limitations on the exercise of the right to vote established by judicial resolution on the legal basis of section 3.1. b) and c) of Organic Law 5/1985 of June 19, now suppressed, are without effect. People whose right to vote has been restricted or annulled due to disability are fully reinstated by operation of law”.*

### Sweden

The right to vote is absolute and cannot be taken away. Support when voting can be given as a part of other social measures that are in place to guarantee the right for everyone to have equal opportunity participate in society.

### Switzerland

The current regulation at federal level assumes that voters are able to inform themselves and form a will in order to vote (capacity to judge). A restriction to vote comes into effect when a comprehensive guardianship is established and/or with the actual entry into force of the advance directive.

In November 2020, a significant majority in the canton of Geneva voted in favour of no longer depriving people who are under comprehensive guardianship of their political rights at the municipal and cantonal level. The cantons of Vaud and Neuchâtel are exploring similar options.

The Federal Council indicated in 2021 that it was ready to address the issue, however, this has not progressed since.

### Turkey

People with advanced dementia and who have a disability report documenting their situation cannot vote. There is no possibility of voting through a guardian or representative.

### Ukraine

Only legally capable persons have the rights to vote and be elected. If a person with dementia was found lacking legal capacity by court, they cannot vote.

### United Kingdom – Scotland

People with dementia have the right to vote. The Scottish Human Rights Commission notes that

everyone has the right to vote for representatives who then make up the legislature. The elections must be free, fair, take place by secret ballot, occur at regular intervals and properly express the views of the electorate. This can be ensured by:

- Not restricting a person right to vote on the basis of their age or physical or mental disability
- Ensuring that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use for older people
- Respecting the right to vote in secret
- Providing support to people to use their right to vote when they wish to do so.



## 7. Consent regarding treatment for persons with reduced capacity

### Austria

A person who has decision-making capacity can only ever decide for themselves whether they want medical treatment or not. Whether a person has the capacity to make a decision is determined by the medical staff during the informed consent interview. The same also applies if a person has a proxy. If the doctor determines that a person concerned does not have the capacity to make a decision, the patient can be supported in the decision-making process by a health care proxy, the elected adult representation, the statutory adult representation or the legal adult representation.

If a person concerned has a representative who has power of representation for medical matters, this representative decides whether medical treatment is to be carried out or not and must decide in accordance with the (presumed) will of the patient. If the view of the person representing the patient diverges from that of the represented person, a court must be called upon to decide. A person, even one who is not capable of making decisions for themselves, must always be informed about the basic features of medical treatments (including nursing or therapeutic interventions).

Living wills represent the will of an affected person if they are no longer capable of making decisions. The will can only be made in person and the person concerned must have the capacity to make decisions when the declaration is drawn up. A living will is valid for eight years, after which it must be renewed. If the person concerned becomes incapable of making decisions in the course of these eight years, the living will nevertheless continues to be binding.

There is a distinction in law between binding and non-binding living wills. A non-binding advance will does not fulfil the formal requirements of living will but must nevertheless be taken into account when determining the will of the person concerned.

Legislation regulates which groups of people have access to palliative support services. This includes “adult palliative patients”, persons who are terminally ill and dying, who are in an advanced stage of disease and have physical or psychosocial symptoms that significantly affect their quality of life. Those seeking an assisted death require a Sterbeverfügung, a legal disposition, which must be done via a notary or a patient advocate, with two separate doctors confirming that the patient is both able to make decisions and has come to the decision on their own.

### Belgium

Patients in full possession of their means and informed by the doctor must be able to refuse or interrupt treatment. If the person is unable to request the interruption or refusal of care, the doctor provides the appropriate care.

### Bulgaria

If the patient is under full guardianship, informed consent must be provided by the guardian. If the patient is under partial guardianship, their consent, as well as that of their guardian is required. At any time, the patient, their guardian or their trustee can refuse proposed medical care and can withdraw given consent. The refusal must be signed in the patient’s medical file. If treatment is refused and this threatens the life of the patient, the chief of the medical establishment can decide to initiate lifesaving treatment. If the individual is unable to consent, the consent may be given by his relatives in written form.

### Czech Republic

For routine procedures (i.e. one that does not involve permanent, irreversible and serious consequences or danger to life or health) and the person with limited capacity understands the procedure (as is appropriate to his or her intellect and free will), it may be carried out on the basis of their consent. In the event of an emergency, Section 35 (1,4) of the Health Services Act allows for treatment to be given without consent.

In the case of more complex procedures (e.g. surgery), about which the person with limited capacity is able to make some judgement (but not sufficient to provide consent), the consent of the guardian is required, defined in section 35 (1,4) of the Health Services Act and section 93 (2) of the Civil Code. However, the opinion of the person with limited legal capacity must also be considered, as the Civil Code protects right to integrity.

In a situation where the person with limited legal capacity seriously opposes such an intervention, even if the guardian consents, the court's approval is required. Where the situation is reversed, i.e. the person with limited legal capacity wishes to have a procedure that the guardian does not agree with, the solution is then the same – court approval is required. This is covered by section 100 of the Civil Code. Additionally, proceedings in this matter can be initiated even without a petition under section 13 of the Special Proceedings Act.

### Denmark

No treatment may be initiated or continued without informed consent given by the patient, with the understanding that the patient has given consent based on adequate information from the healthcare professional. Informed consent may be written, oral or tacit. The patient may withdraw their consent to treatment at any time.

If the patient is deemed incapacitated, lacking the ability to give informed consent, their closest caregiver may give informed consent for treatment. If the patient is under guardianship, informed consent may be provided by the guardian. If the patient has a power of attorney covering personal matters including health conditions, informed consent may be given by the future proxy to the extent that the person has authorised the future proxy to do so.

### Estonia

People with limited capacity are asked to consent to treatment, in so far as they are capable of understanding and participating in decision-making. If the guardian's decision harms the patient's interests, the healthcare provider has the right to disregard the representative's wishes.

By the Law of Obligations Act § 766:

4. *In the case of a patient with restricted active legal capacity, the legal representative of the patient has the rights specified in subsections 1 and 3 of this section in so far as the patient is unable to consider the pros and cons responsibly. If the decision of the legal representative appears to damage the interests of the patient, the provider of health care services shall not comply with the decision. The patient shall be informed of the circumstances and information specified in subsection 1 of this section to a reasonable extent.*

By the Law of Obligations Act § 767:

1. *If a patient is unconscious or incapable of exercising his or her will for any other reason (a patient without the capacity to exercise his or her will) and if he or she does not have a legal representative or his or her legal representative cannot be reached, the provision of health care services is permitted without the consent of the patient if this is in the interests of the patient and corresponds to the intentions expressed by him or her earlier or to his or her presumed intentions and if failure to provide health care services promptly would put the life of the patient at risk or significantly damage his or her health. The intentions expressed earlier by a patient or his or her presumed intentions shall, if possible, be ascertained using the help of his or her immediate family. The immediate family of the patient shall be informed of his or her state of health, the provision of health care services and the associated risks if this is possible in the circumstances.*

In the case of guardians, under the Law of Obligations Act § 767:

2. *Within the meaning of this Chapter, immediate family means the spouse, parents, children, sisters and brothers of the patient. Other persons who are close to the patient may also be deemed to be immediate family if this can be concluded from the way of life of the patient.*

### Finland

Patient autonomy is the guiding principle of social and health care. According to the Patients Act, patients must be treated with their consent. The basic principle of the Act on the Status and Rights of Patients (785/1992) is that the will of patients who are unable to decide on their treatment must also be respected, and that their assessed interests are only taken into account when their own will cannot be ascertained. In cases where the patient is either permanently or for a longer period of time effectively unable to exercise their right to self-determination, the next of kin or other close or legal representative must be consulted before an important treatment decision is taken, in order to determine what treatment would best reflect the patient's wishes, and the consent of the person consulted must also be obtained for such treatment.

### France

The Public Health Code (last amended 2023), the Code of Social Action and Families (last amended 2020) and the Deontology Medical Code (2021) are key pieces of legislation which govern decision-making in relation to health and care decisions, including advance directives and trusted persons.

The person with a neurocognitive disorder has the right to information adapted to their faculties of discernment and to participate in decisions that concern them. Being placed under guardianship does not exempt the doctor from systematically seeking the consent of the person, as long as the latter is capable of expressing their wishes and participating in the decision.

If they are no longer able to do so, their consent will nevertheless be sought; the approach consists of giving full meaning and necessary importance to the opinion of the person unable to give fully free and informed consent. This approach is supported by a collegial assessment which places the patient at the heart of the support.

A "trusted person" can be chosen by the person at any time and where they are not in place, hospitals will ask the person to choose someone upon admission. The trusted person may carry out the following tasks:

- Accompany the person for medical procedures and assist during medical appointments with the consent of the person.
- Help the person make decisions about their health and to help collect consent.

If the person's health means that they can no longer give their views, the doctor (or medical team) must first consult with the trusted person, who must convey the patient's wishes. If a person is under guardianship, they can only designate a trusted person with permission from a judge or family council.

Additionally, people may draft advance directives when they have capacity (usually before the severe stages of the illness) to outline their wishes for care and treatment which will come into effect when they are no longer able to express their wishes.

The person is the only one able to decide what treatment they accept, though doctors must try to convince the person to accept treatments deemed essential. The doctor must provide information and advice and clearly explain the consequences of a refusal. If there is a vital risk, they can intervene, even in the event of refusal by the patient or guardian.

### Germany

Consent is given by the patient or the legal guardian or the person who has a power of attorney.

### Hungary

Under the Law of Health Care (CVIV of 1997), a person under guardianship has limited rights in making health-care decisions. In such cases, the guardian must be involved. In case of contradictory opinions, the person's health must be the deciding factor.

### Ireland

The Assisted Decision-Making (Capacity) Act 2015 allows a person to plan for a time when they may lose capacity in two types of future planning arrangements, known as Advance Healthcare Directives (AHD) and Enduring Power of Attorney (EPA):

- AHD is a document within which a person sets out their wishes about the continuation (or otherwise) of medical treatment if they should become



mentally incapable. It may be valid and enforceable, for example, where one has withdrawn consent to specific medical or surgical treatment. It is not possible to state with absolute certainty that such a directive would be enforced, as it depends on the wording of the document and whether it addresses the precise circumstances which arise.

- EPA is a legal device that can be set up by a person to allow an appointed person to take actions on their behalf in certain circumstances. Having an EPA allows for planning for the possibility that a person may not be able to make certain decisions for themselves at some future stage.

Where a person cannot consent themselves, it is possible to appoint, in advance, someone to act on their behalf – a Designated Healthcare Representative. Based on the information in the person’s AHD, the DHR has the power to:

- Advise on and interpret the wishes of the person (as set out in their AHD) to the healthcare professionals treating the person.
- Agree to or refuse treatment on the person’s behalf.

A Designated Healthcare Representative must make a record of any decision made that relates to an AHD if the person loses the capacity to make certain healthcare and treatment decisions.

### Italy

Informed consent is based on articles 2, 13 and 32 of the Constitution and underpins two fundamental rights of the person: self-determination and health. Every individual has the right to be treated, as well as to receive the appropriate information regarding the nature and possible developments of the therapeutic path, as well as any alternative therapies. Information must be as exhaustive as possible in order to guarantee the patient’s free and informed choice, and therefore their own personal freedom. Consent must be written, free, current, manifest, and aware. There must therefore be adequate information, ensuring an understandable language and taking into account the specific knowledge possessed by the person.

Law 219/2017 “Norme in materia di consenso informato e di disposizioni anticipate di trattamento” (Rules on

informed consent and Advance Healthcare Directives) has reformed a number of aspects of the healthcare relationship between patients and clinicians which identifies the need for “respect for their beliefs, convictions and preferences”. The legislation aims to achieve this in a number of ways:

- Individuals may refuse lifesaving treatments, however, doctors must ensure that all suitable support processes are available, in order that that patients can make informed decisions in full awareness of the consequences.
- Refusal to treatment may be expressed prior to a person becoming incapable, so long as the advanced directive was established at a time when the adult had capacity and was provided with all relevant medical information, including the consequence of refusal to undergo certain treatments.
- Artificial nutrition and hydration are tantamount to treatment, thus they may not be given and kept in place in without valid consent.
- Patients may appoint a healthcare proxy holder, who will have responsibility for interacting with clinicians and caregivers, to express consent or refusal in line with the wishes of the person.
- The will of the person, whether expressed in advance or during at the time, must be complied with, even under emergency conditions (provided that the circumstances allow for it to be acquired).
- Doctors may disregard advance directives only in specific situations defined within the law.

A person lacking legal capacity has the right to have their capacity for understanding and decision-making supported, however, consent, refusal or revocation to treatment still rests with the legal representative as the “amministratore di sostegno” (support administrator) or the guardian in the case of “interdizione” (disqualification). The judge will have made a decision on whether the support administrator should have responsibility for health care choices, and whether the support administrator will solely provide assistance or act on the person’s behalf. The task of giving, refusing or revoking consent will be based on indications already predetermined in the Advance Healthcare Directive or by reconstructing a real biography of the person in relation to certain life choices.

In relation to end-of-life cases, self-determination is also identified as important, with the law specifying that the death should occur in a way “consistent with the self-awareness of personal dignity as built by the individual in the course of life through his rational research and his emotional experiences”.

### **Luxembourg**

Any person wishing to do so may by means of a dated and signed form, appointing a “person of trust” to make decisions regarding their health when the person is temporarily or permanently unable to make decisions regarding their state of health on their own. The person of trust should not be confused with the patient’s support person, who assists the patient with health-related formalities and decisions. The “person of trust” represents the patient and acts as the patient’s “voice” when they are unable to make decisions about their health. The legal guardian of a person with dementia can give consent, if no health counsellor has been appointed.

Legislation provides that, if the patient is permanently unable to express their will, the health care provider must seek to establish their presumed will. As part of establishing this will, the health care provider shall call upon the designated person of trust, if there is one. They may also call upon any other person likely to know the patient’s will. In the absence of a designated person of trust, the interests of the patient placed under guardianship shall be exercised by his guardian.

A patient under legal protection is assisted in exercising their rights according to their ability to understand and receive information adapted to their condition, with consent sought from the person as far as possible. Unless authorised by a court decision to exercise the rights relating to their health alone, the patient under partial guardianship shall exercise his rights with the assistance of the curator.

Additionally, legislation provides that, as far as possible, persons with mental disorders should be treated in the environment in which they live. They may be admitted or placed in a psychiatric ward of a hospital only if serious mental disorders make them dangerous to themselves or others.

### **Malta**

According to the terms of the Mental Health Act, a person shall be deemed able and competent to make health decisions unless certified by a specialist as lacking the mental capacity to do so. Where such certification is in place, consent must be made by the carer of that person. Special treatment may only be given if there is the free and informed consent of the carer together with the Commissioner’s approval that such treatment has been submitted by the responsible specialist, they are satisfied that the consent is free and informed and that there is sufficient evidence-based knowledge that the procedure benefits the health needs of the patient. Should any of the above requirements be missing, then it cannot be said that there is a free and informed consent to treatment, thus resulting in treatment not being given.

### **Netherlands**

The Medical Treatment Contract Act [WGBO] states that any medical treatment, including the use of medical records, must be based on the consent of the person or someone who is authorised to give consent on behalf of that person. Emergency situations and permitted forms of forced care are excluded. A person with dementia can give valid consent if they are mentally capable of doing so. This threshold also applies in case of full guardianship or personal guardianship – the formal deprivation or restriction of legal capacity is superseded by the requirement of mental capacity.

Refusing or withdrawing treatment is the patient’s right. Withdrawal from expensive treatment may result in termination of the contract for medical treatment by the medical professional. Refusal or resistance is honoured, for example, treatment stops when the person is assessed as being mentally incapable for the situation or when it is clear from their behaviour that they do not want treatment.

If refusal is strongly related to the dementia itself e.g. the person is afraid of new situations and does not really resist the treatment itself, there is room to continue the treatment, but according to the principle of proportionality, the benefits of the treatment must be weighed against the violation of human rights (integrity of the body, privacy, freedom of movement).

On 1 January 2020, the Care and Compulsion Act went into effect. Together with the Compulsory Mental Healthcare Act, this piece of legislation replaces the Psychiatric Hospitals (Compulsory Admission) Act and strengthens the legal protection of persons with dementia. The key feature of this new legislation is: ‘no, unless’. This means that care must be provided on a voluntary basis insofar as possible, with involuntary care only implemented if there are no other options. Both laws allow forced treatment and possible involuntary admission to a nursing home or psychiatric hospital. Safeguards are based on decisions of a court or the requirement to hold regular interdisciplinary meetings to discuss continued forced treatment.

The WGBO, the Care and Coercion Act and the Compulsory Mental Healthcare Act all have the same hierarchy of possible representatives in case the person is deemed mentally incapable. At the top are the court-appointed guardians in case of full or partial guardianship. At a second level of representation is the attorney appointed by the person with dementia. At the third level is the partner (official or unofficial). If no representatives have been appointed by the court or by the person themselves and their partner is absent or does not want to represent, the power of representation of the mentally incapable person with dementia can be exercised by immediate family, under article 7:465 of the Dutch Civil Code.

#### **North Macedonia**

All decisions regarding treatment and care are carried out by the person’s attorney.

#### **Norway**

Voluntariness is an important principle in the healthcare system, with patients’ rights and autonomy central in decisions about healthcare. There are four laws regulating the use of coercion in treatment and care services, which generally relate to situations where a person is deemed to be lacking decision-making capacity and the coercive treatment has been evaluated as the best available treatment method in relation to the individual’s condition. Specifically, the benefits of the treatment must be expected to outweigh the intervention and the burden it entails.

If a patient over 18 years old lacks decision-making capacity, healthcare providers may make decisions regarding healthcare that are of minor intrusive nature in terms of scope and duration. Significant interventions may be provided if deemed to be in the patient’s best interest and it is likely that the patient would have given consent to such treatment. Where possible, information should be obtained from the patient’s closest relatives regarding what the patient would have wanted. Such healthcare decisions can be made by the person responsible for providing healthcare, in consultation with other qualified healthcare professionals.

A legal guardian or a person who has been given enduring power of attorney may in some cases consent to treatment, depending on the scope of the guardianship or the power of attorney. Close relatives have the right to be consulted and involved in decisions regarding treatment of a person lacking decision-making capacity.

Voluntariness is also a guiding principle for decisions concerning withdrawal or refusal of treatment, including life-prolonging treatment and the same legislation and principles apply. If the patient lacks decision-making capacity, a guardian or power of attorney can make decisions on behalf of the patient in accordance with the patient’s wishes and interests. However, there are some limitations to the right to refuse treatment. For example, compulsory somatic health care may be considered if the patient’s condition is life-threatening and there is a real risk to their own or others’ health or safety, but the proportionality principle also applies.

#### **Poland**

Medical doctors do not need consent to treat in cases where the patient requires immediate help because their life is threatened and the patient cannot express consent because of their condition or age, or when the doctor cannot communicate with the patient’s legal representative or legal carer/guardian.

When a fully incapacitated person or any other person is unable to express their own will, a doctor must obtain consent from the person’s legal representative or legally appointed carer/guardian. A cumulative

consent is needed when a person who has been fully incapacitated is partly aware of the situation. In such cases the consent is given by the legal representative, carer or guardian, but the patient has right to object to the decision.

A person with reduced capacity has the right to express their will regarding treatment or other personal decision relating to health. A doctor can only initiate treatment if the person is in a life-threatening condition. If the person cannot give consent, a legal guardian or curator is asked to give consent on the persons behalf – where one has not been appointed, a Guardianship Court will be asked to do so.

### Portugal

As a general rule, no intervention may happen without the person's consent, however, in an urgent situation the physician may act without consent. The person is free to and must be informed about the right to refuse treatment and the right to withdraw treatment. If the person is not able to give informed consent or to refuse consent, this must be done by a healthcare proxy or "guardian" (if the guardianship court decision states that the guardian has legitimacy to do it). Additionally, the consent or refusal may be given in advance through a living will. If there is no one to give or refuse consent or a living will, the decision may be made by the Public Attorney.

### Spain

Article 10.5 of the General Health Law (1986) states that "*The patient has the right to complete, continuous, oral and written information on everything related to his process (...), given in an understandable way. In the event that the patient clearly does not want or cannot receive information, it must be sent to family members or legally responsible persons.*" In a situation in which it is impossible to obtain information, no family member can be consulted for the treatment of this information but they are sent to the legal representatives (supervisor, tutor) or to anyone who fulfils the functions of a de facto guardian.

Law 41/2002 concerning on the "basic regulation of patient autonomy and rights and obligations regarding information and clinical documentation" aims to protect the patients' rights in the field of

health care and informed consent. Some key aspects include:

- **Informed consent:** Establishing the principle of informed consent, with every patient having the right to receive clear, comprehensible and truthful information about their state of health, diagnosis, prognosis, treatment options and associated risks. The patient must give consent freely, voluntarily, and consciously after receiving this information. This includes the ability to refuse or request withdrawal of treatment.
- **Capacity to consent:** Recognising the importance of the patient's capacity to give consent. It states that the consent can only be given by the person with legal capacity to consent. If the patient has a reduced capacity or is incapacitated, measures can be applied to ensure that they understand the information provided and participate in decision-making according to their decision-making capacity.
- **Representation and support in decision-making:** In cases where the patient does not have the capacity to give consent themselves, it is necessary to provide for legal representatives or support persons to act in the patient's interest and ensure the patient's wishes and preferences are respected.
- **Revocation of consent:** The patient has the right to revoke consent at any time and the patient must be informed of the consequences.
- **Recording the patient's will:** Establishing the importance of properly documenting the informed consent and any other manifestation of the patient's will in the patient's medical history.

Where the person does not have capacity to communicate their wishes, the patient's representative assumes the responsibility. If the incapacitated person expressed their wishes prior to losing capacity, this must be taken into account by the legal representative or guardian when making medical decisions on behalf of the person. However, the law does not specify what happens in the event where the person cannot make their own decisions and does not have a legal representative.

## Sweden

Different laws govern consent within Sweden, including the Constitution, the Patient Safety Act, Patient Act and the Journal Act.

Doctors must assess the care need by the patient, who has a right to a second opinion. Additionally, the patient must give consent to treatments and has the right to refuse, even necessary life-saving treatments. Only where it is deemed that a psychiatric illness is affecting the decision-making capacity of the person may treatment be given without consent.

A guardian or close relative cannot consent to care or treatment; only the patient can do so. An assessment of the patient's presumed will must be made, even where the patient is unable to give any clear consent.

## Switzerland

Medical treatment is only allowed with the informed consent of the patient; no medical measures may be taken against the will of an adult person who is capable of judgement. However, a necessary medical measure may be taken against the will of a person lacking capacity if the person had not explicitly rejected the measure before losing capacity (e.g. in a patient decree/advance care directive) and if the person authorised to represent the person consents. Any coercive intervention must meet the criteria of proportionality and be necessary for the well-being of the person concerned.

Patients (or, in case of comprehensive incapacity, their representative) are entitled to inspect their patient record and obtain an explanation of its content. They are entitled to receive the documents free of charge and forward them to a healthcare professional of their choice.

Treatment without the patient's consent is only permitted under certain restrictive conditions, usually in cases of involuntary committal. Treatment may only be considered if there are no other, less rigorous alternatives. It must be ordered by a doctor and submitted to a regular review. The concerns of the affected person must be taken into account as far as possible.

The law on the protection of adults contains provisions for the use of coercive measures in sub-areas, namely in the context of a care-related hospitalisation, in the case of retention of patients who have entered voluntarily or in the case of a stay in a residential or nursing care facilities. It also contains provisions to strengthen the legal protection of the persons concerned, under the Swiss Civil Code, art. 382. In detail, the regulations governing measures of restraint and treatment without consent vary from one canton to another.

The third section of the Swiss Civil Code regulates forced hospitalisation. Under Art. 426 Abs. 1, a person with a psychiatric disorder, mental disability or with severe self-neglect may be admitted to an appropriate institution against their will if the necessary care cannot be provided otherwise.

Under Swiss Civil Code, art. 378, the following persons may represent the person lacking capacity of judgement, in order to grant or refuse consent to outpatient or in-patient measures:

- a person appointed in a patient decree or in an advance care directive
- a deputy with a right to act as representative in relation to medical procedures;
- any person who as a spouse or registered partner or who cohabitates with the person lacking capacity of judgement, or who regularly and personally provides them with support;
- any person who cohabits with the person lacking capacity of judgement and who regularly and personally provides him or her with support;
- someone who regularly and personally provides the person lacking capacity of judgement with support;
- the parents, if they regularly and personally provide the person lacking capacity of judgement with support;
- siblings, if they regularly and personally provide the person lacking capacity of judgement with support.

If more than one person has the right to act as the representative, the doctor, acting in good faith, may presume that each person acts with the agreement of the others.

If a patient decree contains no instructions, the representative shall decide according to the presumed wishes and interests of the person lacking capacity of judgement.

### **Turkey**

Consent to treatment is granted by the person themselves, providing they have power of discernment and if not, by his guardian. Where no one is present, treatment will be given without consent. It is only possible to refuse or stop treatment with the written consent of the person themselves or their guardian, ensuring that they understand the risks of doing so.

### **Ukraine**

On the basis of Article 28 of The Construction of Ukraine, Articles 39 and 43 of The Law of Ukraine “The Fundamentals of Ukrainian Legislation on Healthcare” and Article 284 of The Civil Code of Ukraine, informed consent to medical treatment is a free, conscious decision of a person seeking medical help and/or their legal guardians regarding selection and application of diagnostics, prevention and treatment methods. This is based on the information the person receives in an accessible format from their doctor about the state of their health, the purpose of proposed diagnostics and treatment measures, the prognosis and the possible development of the illness, including possible risks to health and life.

The decision to consent to medical treatment should be made freely. It cannot be obtained by external coercion (through threats, psychological pressure from other people or service obligation) or active persuasion by anyone, including the doctor. The decision should only come as the result of personal choice, based on full information about the situation.

The medical professional must provide the patient with information in an accessible format about the state of one’s health, purpose of proposed diagnostics and treatment measures, prognosis of the possible development of the illness, including possible risks to health and life. If information about the illness can worsen the state of health of the patient or hinder the treatment process, medical professionals have the right to provide incomplete information about patient’s health and limit their access to certain medical documents.

In cases where a patient has been found to lack legal capacity, medical intervention is done with consent from the legal guardians of the patient. There is no need for consent from the patient or legal guardians unless there are signs of a direct threat to the life of the patient and if there are objective reasons why gaining consent from the patient or legal guardians is impossible.

A patient who has reached full legal capacity and understands their actions and can control them has a right to refuse treatment. If the legal guardian of the patient refuses treatment and it can have dire consequences, the doctor must inform protection and care services about it.

### **United Kingdom – Scotland**

Under common law in Scotland, it is reasonable in an emergency to take the necessary action to safeguard a person who is unable to consent in situations where, without treatment, they may be at risk of significant harm (e.g. someone who is unconscious after an accident or who is unable to consent because of mental disorder such as dementia, and the nature of their injuries were such that a significant delay in treatment could lead to a significant risk to their health).

The Adults with Incapacity (Scotland) Act 2000 makes provisions for the for medical treatment for adults who are not able to consent. These provisions should be used except in emergency situations described above.

In Scotland, Part 5 of the Adults with Incapacity (Scotland) 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. Any proposed treatment should give effect to the principles of the adults with incapacity (Scotland) Act.

Treatment cannot automatically proceed if a welfare attorney or guardian or a person authorised under an intervention order with relevant powers has been consulted and refuses to consent. There is a mechanism for an independent opinion to resolve any

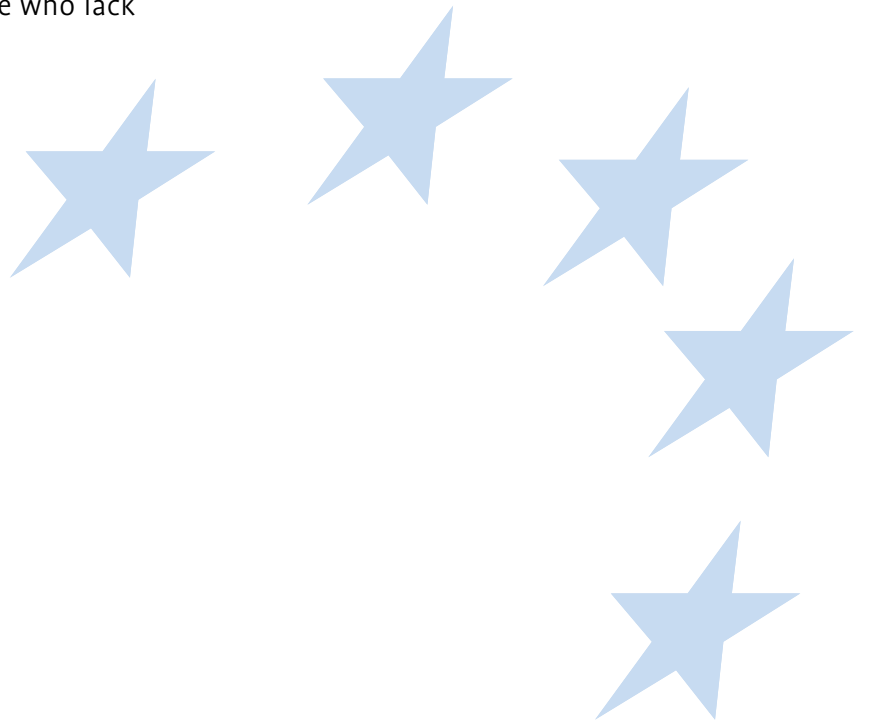
such disagreement. The dispute resolution procedures are in section 50 of the 2000 Act.

Advance decisions to refuse treatment made by an adult in the event that they lose capacity to make decisions in the future do not have any formal status under the 2000 Act in Scotland. However, if a clinician is aware of or provided with a competent advance planning document refusing an intervention, the expectation would be that this would be regarded and respected. The principles of the Adults with Incapacity Scotland Act include the duty to consider the past and present wishes of the adult. Therefore, clinicians would be expected to take the advanced decision into account in their decision-making process, despite it not being legally binding.

The Mental Welfare Commission for Scotland has produced a good practice guide: “Right to treat? Delivering physical healthcare to people who lack capacity and refuse or resist treatment”

The Mental Health (Care and Treatment) (Scotland) Act 2003 makes provisions for how people can be treated if they are unwell and need treatment for mental disorder. Mental disorder, as defined by the Act means mental illness, learning disability or personality disorder, and also includes dementia. The Act provides for an individual to make a written statement when they are well, setting out how they would prefer to be treated (or not treated) if they were to become unwell in the future and their ability to make decisions about their treatment becomes significantly impaired. This is called an advance statement and is relevant only to treatment for mental disorders as defined by the 2003 Act.

Section 50 of the Adults with Incapacity Act (as amended) sets down a procedure for resolving disagreements between a guardian or attorney and the medical practitioner.



## 8. Consent to research for persons with reduced capacity

### Austria

In principle, a person with decision-making capacity can only ever give consent to participate in a research project themselves. Participation in research projects is regulated in the General Civil Code, which defines that a person with a health care proxy or an adult representative may not in principle consent to the participation of the represented person in a medical research project if the physical integrity of the person is endangered by the participation.

There is, however, the exception that participation may be consented to if such participation may be directly beneficial to the health or well-being of the represented person. If there is no positive opinion from the competent ethics committee, a court must be consulted before participation can be initiated. If the represented person indicates to the court that they do not wish to participate, this wish must be accepted. Action can be taken against this wish if non-participation would significantly endanger the welfare of the represented person. In addition to court approval, a favourable opinion from an ethics committee is also required.

### Belgium

According to article 20 of the medical code of ethics, 1.5, “incapacitated adults”, a person may be appointed as “designated mandatory” in the event of the person’s incapacity to express their will or to give consent. Issues around consent to participate in research and use of medical records are governed by the Medical Deontology Code and article 6.1.a of the GDPR.

### Bulgaria

Nobody may be subjected to medical, scientific or other experimentation without their voluntary written consent. It is forbidden for people under guardianship to participate in medical and scientific research. No other person can give consent for research in place of the person who is incapacitated.

### Czech Republic

Under Act No. 378/2007 Coll., Act on Medicinal Products and Amendments to Certain Related Acts (the Medicinal Products Act), section 52 on the protection of certain groups of trial subjects states:

2. *Clinical trials may also be carried out under the conditions laid down in this Act in specific groups of subjects, including persons (...)  
whose legal capacity has been limited by a court.*
3. *Clinical trials may be carried out on persons referred to in paragraph 2 only if they give their free and informed consent and if there is scientifically substantiated evidence justifying the expectation that participation in the clinical trial will have a direct therapeutic or preventive health benefit for these persons that outweighs the associated risks and burdens, or that inclusion in the clinical trial will be the only possibility for them to stabilise or improve their adverse health condition.*

Where the court has ruled that the patient has limited capacity and cannot make decisions about issues related to the provision of health services, those with proxy powers can consent to research on behalf of an individual.

### Denmark

For a person with dementia to participate in research, they must be informed in writing and orally about the content and foreseeable risks and benefits of the scientific research project before giving consent. The informed consent must be written, dated and signed or given via electronic signature. A scientific research project cannot be carried out if the person objects either orally or by their actions.

### Estonia

The ability of guardians to give consent for research depends on what kind of activities have been granted in the guardianship. Conducting clinical drug research



is regulated by the Medicinal Products Act, with all clinical trials of human drugs are processed by the Ethics Committee for Drug Research.

### Finland

People with dementia are not necessarily excluded from research but it can be difficult, as it has to be shown that the person has given consent and understood the context correctly. In medical research an ethical review is always required, in human sciences review applies only to precisely defined research configurations. Additionally, the Medical Research Act (499/1999) states:

*Section 6 “Medical research on persons may not be conducted without the research subject’s informed consent in writing. Exceptions to this may be made where consent cannot be obtained owing to the urgency of the matter and the patient’s state of health and the measure is expected to be of immediate benefit to the patient’s health. If the research subject is not able to write, he or she can give the consent orally in the presence of at least one witness who is not dependent on the research. It is allowed to deviate from the requirement for written consent in research other than clinical trials on medicinal products also when giving personal data would be in contrary to the research subject’s interests and the research will only involve minor stress to the research subject and is not harmful to the research subject’s health. Oral consent may then be given without the presence of a witness, and the personal data of the research subject are not recorded in the research documents.”*

*Section 7 “People who, owing to a mental health disorder, retardation or other similar reason, do not have the capacity to give their consent to research may be research subjects only where it is not possible to obtain the same scientific results using other research subjects and where the risk of harming or distressing the research subject is only very slight. It shall be further required that: (1) the research should be likely to be of direct benefit to the research subject’s health; or (2) the research should be likely to be of special benefit to the health of people in the same age group or with the same state of health.”*

### France

The Committee for People’s Protection (CPP) is responsible for issuing a prior opinion on the conditions of validity of any research involving the human person, with regard to the criteria defined by article L 1123-7 of the Public Health Code (CSP).

The project leader has to issue a file including how they will deal with people’s protection and the way they obtained an informed consent. They are also responsible to seek people’s informed consent after an interview either with the person or their caregiver (if the state of the disease doesn’t not allow the first option anymore). But there are conditions such as proving that there is a guardianship in place.

*Article L1121-1 states: “The person whose participation is requested is informed of his right to have communication, during or at the end of the research, of the information concerning his health, held by the investigator or, where applicable, the doctor or the person qualified who represents him. The person whose participation is requested or, where appropriate, the persons, bodies or authorities responsible for assisting him, representing him or authorizing the research are informed of his right to refuse to participate in the research or to withdraw his consent or, where appropriate, its authorization at any time, without incurring any liability or prejudice thereby.”*

*Article L1122-1-1 states: “No research mentioned in 1° of Article L. 1121-1 may be carried out on a person without their free and informed consent, obtained in writing, after they have been provided with the information provided for in Article L. 1122. -1. When it is impossible for the person concerned to express their consent in writing, this consent may be attested by the trusted person provided for in Article L. 1111-6, by a member of the family or, failing that, by one of the relatives of the person concerned, provided that this person of confidence, this member or this relative is independent of the investigator and the sponsor.”*

### Germany

Consent is given by the patient or the legal guardian or the person who has a power of attorney.

### Hungary

Consent for research is determined in relation to the Law of Health Care CVIV 1997.

### Ireland

The Health Research Regulations 2018 place additional consent requirements for the processing of personal data for research in Ireland. Data protection requirements must be adhered and valid consent for the use of personal data for future research purposes must be sought. Such consent, while it may be broader (i.e. not as specific as research for a given project), it needs to be as informed as possible and the choices made by the participant have to be appropriately recorded and documented.

The Health Service Executive (HSE) has published a National Policy for Consent in Health and Social Care Research Revision in light of the commencement of the Assisted Decision-Making (Capacity) Act 2015. The new national policy was published in June 2023.

Prospective research participants must give consent to participate in research and must be given all of the necessary information in a way that is understandable for them, and with sufficient time to consider it, before exercising their choice. For consent to be specific the following must apply:

- Consent must be specific about the purpose(s) of the study and the associated data processing.
- While consent for secondary research use of identifiable personal information or identifiable biological material may have to be broader rather than specific, the consent process must include as much detail as possible about the potential secondary use of the personal data or the biological material.
- Information and considerations related to the research intervention should be separate from those related to consent for data processing activities (usage, sharing etc.).

There should be no reasonable doubt that the research participant wants to express their agreement to participate in the study and, when relevant, allow the processing of their data for the research. Consent should be recorded by way of an active choice to opt-in

(by way of either written, verbal, electronic, or other formats). It must be recorded and retained, with a copy provided to the participant where they are able to receive it. Additionally, participants must have the right to withdraw consent at any time.

A person who may have expressed a will and preference to participate in healthcare research, will be able to do so even when they lack capacity, so long as it is listed in the decision support agreement under the Assisted Decision-Making (Capacity) Act 2015. This means that their decision supporter would be in a position to help them to engage in the research. Where a person lacks capacity and does not have an appointed decision supporter in place who can consent on their behalf, the Health Research Consent Declaration Committee can assess applications for consent and make consent declarations

### Italy

Consent for research is governed by article 32 of the Constitution and by the European Regulation n. 536/2014 on clinical trials of medicines for human use.

The collection of informed consent is defined by the AIFA (Italian Medicines Agency) guidelines, consent for the National Coordination Centre of Ethics Committees must be given by a capable person, be expressed in writing (since it cannot be assumed or implied), be current for the entire duration of the trial (since the initial consent is not sufficient if the conditions and procedures of the trial are changed). The moment of signing establishes a personalised information path during which the potential participant must have the opportunity to receive and discuss relevant information regarding:

- The reason/purpose of the study
- The phases that characterise it and the procedures that will be implemented and the inclusion and exclusion criteria
- The description of the investigational therapy (risk and benefit, efficacy, side effects, dosage), the number of participants and the duration of the treatment and study
- The deadlines for sampling/exams and for control and follow-up visits, rights, and the freedom not to participate.

The informed consent form must be divided into two essential parts, the information section and the section relating to the acquisition/revocation of the consent signature, and must be:

- Conformed to the principles of the Declaration of Helsinki (as amended) as well as the Oviedo Convention
- Approved by an Independent Ethics Committee
- Structured in a question-answer model to facilitate understanding and dialogue or by paragraphs to facilitate reading
- Free from phrases that might make it appear that the subject or their guardians are giving up their legal rights or that the investigator be relieved of any negligence faults
- Provide for the possibility of compensation by an insurance company for any damage caused to the subject
- Updated with the new information regarding the study protocol - the modifications must be approved by the Ethics Committee and the patient must be informed and express a new consent.

For people unable to express valid consent, Legislative Decree 24 June 2011, n. 318 implementing Directive 2001/20/EC relating to the application of good clinical practice in the execution of clinical trials of medicinal products for clinical use and European Regulation 536/2014 identify in the figure of the legal representative the person who must be involved in the information process and from whom informed consent must be collected. An exception is the case of clinical trials in emergency situations where it is possible to acquire informed consent after the decision to include the subject in the trial, however respecting a whole series of conditions.

In the case of a person for whom there is evidence of a reduced ability to express consent, and who lacks legal representation, the doctor/researcher has the task of trying to “measure” the ability to make conscious choices. In the case of a person judged incapable, the doctor/researcher has, according to the law, only two alternatives:

- Request the appointment of a legal representative (“amministratore di sostegno” support administrator with the power to choose healthcare/guardian)
- Exclude the person from the trial.

In any case, conducting a clinical trial in the case of incapacitated subjects is legitimate only if all of the following conditions are met:

- The clinical trial is directly associated with a clinical condition that affects the subject
- It is not possible to obtain data of similar validity on persons able to provide their informed consent or by other research methods
- There are scientific reasons to believe that participation in the clinical trial leads to:
  - a direct benefit greater to the capacitated person than the associated risks and burdens
  - or to the population represented by the incapacitated subject concerned, certain benefits if the clinical trial is directly associated with a life-threatening or debilitating clinical condition affecting the person and if such a trial involves only minimal risk and burden for the incapacitated person concerned with respect to the standard treatment applied to their condition;
- No financial incentives or benefits are given to the subjects or their legal representatives, with the exception of an indemnity for expenses.

### Malta

A person with a mental disorder may not be subjected to clinical trials or other medical or scientific research unless:

- Free and informed consent is given by the said person
- An independent specialist appointed by the Commissioner examines the person and certifies in the clinical records that in their opinion the person is capable to give free and informed consent and that the expected benefits of the trials or research are likely to outweigh any potential harm to that person
- There is approval from the ethics committee appointed by the Minister under the Clinical Trials Regulations.

If the person cannot give the free and informed consent per above, then such person may only be subject to clinical trials or other medical or scientific research if:

- The Commissioner is satisfied after assessment by two independent experts, one of whom shall be a specialist in mental health, that the expected benefits of the trials or research are likely to outweigh the potential harm to that person
- There is approval of the responsible carer
- There is the approval of the ethics committee appointed by the Minister under the Clinic Trials Regulations.

### Netherlands

Article 4 of the Medical Research Act contains specific provisions on consent. Permission is required from a committee to conduct research with patients. Scientific research is not allowed in patients who are unable to provide consent unless the patient himself can benefit from this research. There is also an exception for research (such as into dementia) that can only be carried out with the cooperation of the specific patient group itself, where the risks for them are negligible and the disadvantages minimal.

Where the person cannot give consent themselves, permission from a representative is required e.g. from a court-appointed plenary or personal guardian, an attorney appointed by the person himself, his or her partner or a close relative. Extra protection is laid down in this law under article 6 because strict rules apply regarding informing the patient and his representative before consent can be given, and that the patient can terminate his participation in the research at any time without stating reasons or liability.

### North Macedonia

Powers of attorney can consent on behalf of the person with incapacity so that they may participate in research.

### Norway

A person must be able to understand information about the research project, the consequences of participation and to be able to make an informed decision about participation. This normally requires

that people participating in research must have decision-making capacity. The principle of informed consent is regulated by the Health Research Act.

However, there may be situations where participation in research without decision-making capacity is permitted under certain conditions. This is particularly applicable to research that is of significant importance to society and where it is not possible to obtain consent from individuals with decision-making capacity. In such cases, exceptions to the requirement of decision-making capacity can be sought through ethical committees and provisions of the Health Research Act.

Guardians and enduring power of attorneys are not able to consent to research participation on behalf of people deemed to lack capacity. For participation in research projects, especially involving individuals without decision-making capacity, specific provisions of the Health Research Act apply. Exemptions from the consent requirement must be sought through an ethical review process and must meet the following conditions:

- The research cannot be conducted with participants who have decision-making capacity.
- The research is of significant importance to society.
- The research cannot be conducted in any other appropriate manner.
- It is not possible to obtain consent at a later time when the individual potentially becomes capable of decision-making.

### Poland

Participants in clinical trials (including those for medical devices) must give their informed consent when deciding to take part in the trial. For each trial, specific consent documentation must be prepared and approved by the ethics committee. Informed consent is a written statement of intent, dated and signed, made freely by any person capable of making such statement or, where the person is not capable of making such statement, by their legal representative. The statement also contains a note to the effect that it was made after the person had been duly informed of the nature, significance, implications and risks of the clinical trial.

If the informed consent cannot be given in writing, consent given orally in the presence of at least two witnesses will be deemed equivalent. A note must be made in the trial documentation if consent is given in this manner. Before obtaining informed consent, the investigator must provide the participant or their legal representative information about the aim of the trial, procedures to be used, etc, in an understandable manner and without exerting any influence, in oral and written form, with certain information set forth in the Regulation of the Ministry of Health of 2 May 2012 on Good Clinical Practice (e.g. information about the aim of the trial, procedures to be used etc.).

Matters relating to consent to research are regulated by the Act on Medical Profession and Dentists. Participants in medical research must give their informed consent. A person who has been fully or partly incapacitated is required to provide written assent if they are able to consciously express their opinion. When this is not the case, consent can be given by their legal representative. If the legal representative refuses to give consent, a guardianship court can overrule this decision if it is deemed in the best interest of the patient. Guardianship courts may also give consent in case of participants with the capacity to act in law but unable to consciously express their opinion. In addition to the decision of the legal representative, the incapacitated participant may withdraw from the study if they are able to express an opinion.

### Portugal

Clinical trial participation of incapacitated adults who have not given or not refused informed consent before the onset of their incapacity is only allowed if the informed consent of the legal representative has been obtained and the consent respects the presumed will of the participant. The person not able to give informed consent must also have been given information according to their capacity of understanding regarding the trial, the risks and the benefits. The explicit wish of the person able to form an opinion must be respected by the investigator.

In a clinical trial with intervention (i.e. one which includes a change, influence or programming of health care, behaviour or knowledge of participants

and caregivers to discover or verify health effects) some additional requirements must be fulfilled. For example, the clinical trial must be essential to validate data obtained in clinical trials on persons able to give informed consent or by other research methods and must relate directly to a life threatening or debilitating clinical condition affecting the incapacitated adult. Additionally, the clinical trial must have been developed in such a way as include an aim to prevent the disease, reduce discomfort or fear, rehabilitate and/or address any other foreseeable risk related to the disease stage. Finally, the risk threshold and the degree of distress shall be specially defined and constantly monitored.

Where a person is deemed incapable of making decisions, the healthcare proxy and the guardian can consent on behalf of a person, if the court decision has specified this power.

### Spain

The Law 14/2007 of 3 July on biomedical research and consent to participate in research regulates biomedical research and establishes the ethical and legal principles to obtain informed consent of participants in medical and scientific research. The key aspects of the law are:

- Regulate research in the field of health, ensuring the protection of the rights, health, and safety of participants in scientific studies.
- Participants must receive clear and detailed information about the objectives, methods, possible risks and benefits of the research, with informed and free consent obtained from the participants before their inclusion in the study.
- The law establishes that only people who have the capacity to understand provided information and make decisions can give their informed consent. In the case of incapacitated people, informed consent of their legal representative is required.
- Researchers are obliged to protect the confidentiality of the information collected during the research and ensure personal data protection of the participants according to current legislation regarding to data protection.
- The law establishes the obligation that, prior to commencing a study, all biomedical research

projects must be evaluated by a Research Ethics Committee (CEI), which has the function of ensuring the protection of the rights and safety of the participants in the research.

- Biomedical research projects must be registered in a public registry, which provides transparency and supervision of the research activity.

The Law 14/2007 of 3 July also indicates, in Article 4 regarding informed consent and the right to information in point 2, that “*consent will be given by representation when the person is legally incapacitated or is a minor, as long as does not exist another alternative for research*”. Consent provision by representation will be given to the research undertaken and will be carried out with respect to the dignity of the person and for the benefit of their health.

### Sweden

Research must go through an ethics board for approval. In the case of incapacitated adults, others may not consent on their behalf.

### Switzerland

Involvement in a research project is only permissible with the informed and express consent of the patient capable of judgement. He or she can refuse to participate without having to justify this decision or fear disadvantages for his or her treatment. A consent, once given, can be revoked (Bundesgesetz über die Forschung am Menschen (Federal Act on Research Involving Human Beings, Art. 7).

Art. 24 Federal Act on Research Involving Human Beings states that a research project with an expected direct benefit may be only carried out with incapacitated adults if:

- Documented consent has been given by the person concerned in a state of incapacity; or documented consent allows this
- The legal representative, a designated trusted third party or the next of next of kin have given their written informed consent, if no documented consent is available; and
- The person concerned does not recognizably object to the research action by means of statements or corresponding behaviour.

A research project with no expected direct benefit may only be carried out with incapacitated adults if, in addition to the above requirements, it:

- Involves minimal risks and burdens
- Is expected to yield significant findings that may provide longer-term benefits to persons with the same disease or disorder or in the same condition in the longer term.

### Turkey

People with dementia can be included in medical research as long as it will have direct benefit for them. They cannot be included in studies where it is only for research purposes, even where they provide consent. A person with dementia may be allowed to participate in research by consent of their guardian, provided that it has the potential to be of direct benefit to the person. If research that is likely to be beneficial to the person is not permitted by the guardian, it is possible to obtain permission by applying to the court.

### Ukraine

Legally capable persons are allowed participate in research. In such cases, the person is notified about all the details of research. They have unlimited time to review the information and have a right to consult with third parties about the research and their participation in it. The consent to participate in research is given in written form. According to article 39 of The Law of Ukraine “The Fundamentals of Ukrainian Legislation on Healthcare” conducting scientific-research experiments on people who are ill is forbidden. For persons lacking legal capacity, the guardians cannot consent to research participation on their behalf.

### United Kingdom – Scotland

There is a presumption in favour of capacity in Scots law. Only where there is evidence of incapacity can that presumption be overturned. The definition of incapacity contained in the Adults with Incapacity (Scotland) Act 2000 is relevant. People with a diagnosis are therefore able to consent to participate in research unless there is evidence they do not have capacity to do so.

Section 51 of The Adults with Incapacity (Scotland) Act 2000 sets out the circumstances where there is authority for research participation when a person does not have capacity to consent to participation in the research. There are specific conditions, one of which is that consent has been obtained from a guardian or attorney who has relevant powers to consent to research on behalf of the person. One of

the overriding conditions to involving adults with incapacity in research is that similar research cannot be done by involving adults who can consent.

Regarding Clinical Trials, the Act permits participation of an adult who does not have capacity to consent to research without the consent of a guardian, attorney or nearest relative under certain conditions.



## 9. Powers of attorney

Individuals have the ability to nominate another person to make decisions on their behalf in the event that they become unable to make or communicate decisions for themselves. These measures are generally considered as preferable to guardianship, as it allows the individual to determine who will make decisions over their affairs and which aspects (e.g. financial, healthcare etc.) which the proxies may make decisions.

### Austria

There are different types of proxy:

- Health care proxy: Every person who is capable of making decisions can appoint a person to take over certain tasks for them in the event of incapacity.
- Elected adult representation: An elected adult representative can be chosen by the person concerned even if they are no longer fully capable of making their own decisions.
- Statutory adult representation: If an affected person can no longer choose representation for themselves, if they harm themselves or if they can no longer care for themselves, this form of representation comes into consideration. In the case of statutory adult representation, grandparents, children, grandchildren, siblings, the spouse or a civil partner can represent the person (for this it is necessary to live together in the same household for three years). A person may also have several legal adult representations, whereby the areas of competence of the individual representations may not overlap.
- Legal adult representation: In this case, the person concerned can no longer manage personal affairs by themselves due to an impairment of decision-making capacity without possibly harming themselves. Persons who can represent them in this case are those named in an existing adult representative order, close persons or adult protection associations. If representation by an adult protection association is also not possible, a notary public or a lawyer can also be appointed for this function.

The court acts as a supervisory authority if, for example, there is a disagreement between the representative and the represented person regarding consent to medical treatment, or if concerns a permanent change of residence of the represented person abroad.

### Belgium

The Administration of the Person and Property Act came into force on September 1, 2014. For extrajudicial protection measures, a mandate can be appointed via the court or the notary. The mandate must always be capable of managing the person to be protected for the future. For judicial protection measures, the protected person remains capable of all acts for which the Justice of the Peace has not ordered assistance or representation. Judicial protection covers protection of the person (exercise of parental authority, choice of place of residence, etc.), as well as protection of property (acceptance of a donation, taking out a loan, disposal of property, etc.).

Priority is given to the assistance regime: certain acts may not be the subject of representation or assistance (26 acts listed in article 497/2 of the civil code). Powers of attorney and abuse are handled by the Justice of the Peace.

### Bulgaria

When a person is in full capacity, they may give power of attorney to third party for any actions. When the person is under guardianship, the power of attorney loses its effect. The power of attorney must be signed before a notary and must have notary certification of the signing. There is an electronic register for powers of attorney with notary certification. A person may withdraw given power of attorney.

### Czech Republic

Powers of attorney do not require court approval and the documentation of medical information. The signature of the power of attorney can be notarised, which is more often recommended. The rules for granting a power of attorney are regulated by Act No. 89/2012 Coll. in the Civil Code.



The law distinguishes two basic types of authorisations: Special and General powers of attorney for representation. A Special power of attorney authorises the principal to perform specified acts. A General power of attorney, on the other hand, is an authorisation to perform all legal acts without any limitation on the part of the principal. General powers of attorney may also be drawn up for an indefinite period. This option will be used especially by principals who need to be represented in various acts for a long period of time. This is usually the case, for example, with older persons who may authorise family for these purposes. When a General power of attorney document is drawn up for an indefinite period, it can be terminated in the following ways:

- Revocation by the principal
- Termination by the attorney-in-fact
- Death of the principal or the agent

Under this legislation, a preliminary declaration also can be made in the anticipation of legal incapacity, where a person may express a wish that their affairs be managed in a certain way, by a certain person and/or that a certain person become their guardian.

Powers of attorney are not monitored. Additionally, the authorised person cannot make independent decisions, they may only make decisions on the instructions of the one who issued the power of attorney.

### Denmark

Any person over the age of 18 with full capacity can create a power of attorney. Powers of Attorney may be limited to a single task or to a limited part of the lives of people with dementia. However, the power of attorney can also be drawn up to cover a wide range of activities. There are three types of power of attorney: General power of attorney, future power of attorney and digital power of attorney.

A person with dementia may appoint their own proxy without necessarily involving a lawyer. The power of attorney takes effect on the day the power of attorney is granted. The Agency of Family Law can activate the power of attorney when the person with dementia has lost the capacity to act due to dementia.

There are no requirements for monitoring proxies. People with dementia who do not have capacity and can no longer look after their own interests cannot create a power of attorney. In that situation, a guardianship will be relevant.

All use of force must be registered and reported to the authorities within 24 hours of the incident. Professional staff (e.g. in care homes) must use the Social and Housing Authority's special reporting form and submit the form to the municipality. The citizen or a representative of the citizen can complain about measures taken under the Services Act.

### Estonia

In the case of smaller financial transactions, one person can give another person or institution a power of attorney, which is formalised by a notary, with authorisations taking effect immediately. Although patient wills are not common, legislation allows for their use. The granting of authority to represent the principal is regulated by an Act on the General Part of the Civil Code section 118 which states that:

1. *The principal grants the authority for their representation by making a corresponding manifestation of intention to the representative, to the person with whom the transaction that requires the authority is to be carried out, or to the public.*
2. *Where the representations or conduct of the person acting as the representative lead another person reasonably to believe that the person acting as the representative has been granted authority by the principal to carry out a certain transaction, and the principal knows or should know that the person is acting as the principal's representative and the principal permits such conduct, the principal is deemed to have granted the person the corresponding authority.*
3. *Where the law prescribes a certain form for a transaction and failure to follow such form would render the transaction void, the authority to represent the principal in carrying out the transaction takes the same form.*

Powers of attorney are not controlled or monitored, however, abuses are punishable.

## Finland

Continuing power of attorney (i.e. anticipating the need for support) is a more flexible and lighter way of organising the management of affairs for the future than appointing a guardian. The authorisation is recorded in a power of attorney, in which one can name the person who will have the right to manage one's affairs. One can also state how personal affairs may be managed and specify how the attorney's activities are to be supervised. A continuing power of attorney can be drawn up by an adult who understands the content and importance of the document. Approval is not required, with the attorney only sending the power of attorney for verification when a person is no longer able to manage one's affairs.

A continuing power of attorney must be made in writing. Two other qualified witnesses must be present when the granter signs the document or acknowledge that their signature is on the document. After this, the witnesses verify the document with their own signatures. The witnesses must be aware that the document is a continuing power of attorney but the granter does not need to explain the details to them. Before the appointment of the attorney, it should be confirmed that the proposed attorney is prepared to accept the responsibility when required.

The continuing power of attorney document must include the following:

- A statement that the document in question is a power of attorney.
- The granter, i.e. the author of the power of attorney.
- The attorney, i.e. the person to whom the granter gives the right to represent them in the management of their affairs.
- The matters that the attorney is entitled to handle on behalf of their granter.
- Very detailed instructions on how the property and matters should be managed can often be included in the power of attorney.
- A condition according to which *“the authorization will enter into force when the granter becomes incapable of managing their affairs because of an illness, disturbance of mental capacity, declining state of health or some other similar reason”*.

One must obtain a medical certificate stating that the granter is no longer able to handle their affairs and also be prepared to show the power of attorney to the physician so that they can ensure that the attorney has the right to obtain a medical certificate on the granter. The Digital and Population Data Services Agency (DPDSA) or Guardianship Services are responsible for the confirmation of the attorney.

Different parties may have differing views on how the granter's affairs should be managed and the attorney's duty of confidentiality may also cause distrust. In unclear situations, the discussion with the attorney would be the first measure, the second is to contact Digital and Population Data Services Agency. It is also possible to file a complaint regarding the activities of the attorney. The guardian usually has the right to be informed of the content of the complaint and the complainant.

It is also possible to file a complaint with the Parliamentary Ombudsman or the Chancellor of Justice instead of DPDSA.

## France

A power of attorney consists of a person (the principal) designating another person (the agent) who may act in their name for the performance of one or more acts that the principal will have previously decided.

In France, the person who consents to a power of attorney always has all of their rights, as in they may themselves always carry out the act(s) for which they have given power of attorney. However, the principal also remains responsible for acts that the agent may carry out. Issuing a power of attorney therefore implies a relationship of trust with the agent.

A power of attorney can take the form of a bank power of attorney, a power of attorney for acts of administration (management of day-to-day business), a power of attorney for acts of disposition (relating to will) or an electoral power of attorney (power of attorney to vote). Powers of attorney are limited in instances where the capacity of the person is too altered. The agent, for their part, could be suspected of carrying out operations that do not comply with the wishes and interests of the principal.

For the power of attorney to be valid and to avoid being subject to challenge, it must be carried out before the possibility of a loss of capacity of the principal. Where this has not been done, it may not be accepted and could possibly be considered void.

### Germany

People with dementia can appoint a person they trust as a power of attorney. These are based on possible decisions related to:

- Property and financial matters
- Non-property matters like health questions, health care, stay determination and accommodation, measures involving deprivation of liberty and/or medical coercion.

They are not fundamentally monitored. If someone has doubts that the authorized representative is behaving correctly, they can contact the guardianship court.

### Hungary

The forms of powers of attorney are controlled in section 67 of the Code of Civil Procedure.

### Ireland

An enduring power of attorney (EPA) is a legal device that can be set up by a person (the donor) prior to losing capacity, to allow a specially appointed person (the attorney) to take actions on the donor's behalf in certain circumstances. An EPA made on or after 26 April 2023 only takes effect if registered with the Decision Support Service (DSS) within three months of the donor becoming incapacitated and unable to manage their affairs. The DSS must be notified of the incapacity and accept that fact. An EPA that was made before 26 April 2023 only takes effect if registered with the Office of the Ward of Courts.

EPAs do not cover decisions about medical treatment – these are covered by an Advance Healthcare Directive, which can also be set up in advance of the person losing capacity. Although the Assisted Decision-Making (Capacity) Act is now the law governing the creation and monitoring of EPAs, the process of making an EPA has not changed. Those made before the Powers of Attorney Act 1996 remain valid.

The DSS has responsibility for supervising and monitoring EPAs to ensure that the donor's interests are protected.

### Italy

Powers of attorney can be special (i.e. for specific single transactions) or general (for all transactions of the principal). The power of attorney can be given to a single person or to several people. In the latter case, the principal establishes whether the representatives can also operate separately or must act jointly.

Powers of attorney can be received from notaries who, as per article 47 of the Notarial Law, must interpret the will of the parties and ascertain that what the parties want corresponds exactly to their will. They have the power and duty to ask the parties all questions that allow them to determine if the parties at that moment possess the ability to understand and are in a psycho-physical state to freely express their will.

Notaries therefore cannot receive deeds from persons who are not capable of understanding and willing or who are more simply unable to respond to the above assessments. In some cases, such as health conditions or advanced age, the notary may request a medical certificate certifying the subject's capacity for self-determination and their ability to understand.

Third parties can monitor the proxies by requesting that the representative (holding the power of attorney) deliver a copy to the proxies. Furthermore, the power of attorney can always be revoked and nullified due to the supervening incapacity of the person represented (or of the representative), bankruptcy, or the expiration of the terms (if set) for which the power of attorney was conferred. If the attorney acts "without power" or exceeds the limits of the powers that have been conferred on them or acts despite the revocation of the power of attorney, the contract made by them is ineffective (though it may eventually be ratified by the person concerned).

### Luxembourg

A draft law on the future protection mandate has been introduced, which aims to create a new extrajudicial protection measure, known as the "Future Protection Mandate". This contract will allow any adult to appoint,

in the event they are unable to take care of their interests by themselves, one or more representatives who agree to represent them in civil matters. This contract provides for the protection of the person and property.

The principal may appoint one or more natural or legal persons with the task of supervising the proper execution of the mandate of future protection.

Any person with dementia may apply to the guardianship court for the purpose of challenging the implementation of the future protection order or for a ruling on the conditions and modalities of its execution. The guardianship court may, at any time, terminate, in whole or in part, the future protection mandate if the way in which the agent is acting is likely to endanger the interests of the principal.

### **Malta**

There are two types of powers of attorney, special power of attorney and general power of attorney. The former will authorise a third party to act in specific matters (for example the signing of a contract) whilst the latter gives the power to act on behalf of the individual in all aspects of life. In all cases, the grantor needs to sign and date the power of attorney in front of a notary. If the grantor does not have the legal capacity to sign the power of attorney, the document is considered null.

Every person, so long as they have a relevant juridical interest, has the right to file an application in court to address the misuse of powers of attorney.

### **Netherlands**

In practice, all continuing powers of attorney are drawn up with the cooperation of the civil-law notary and using model forms made available by them. The number of continuing powers of attorney is estimated at approximately one million. The attorney can be appointed by the grantor for all types of decisions and most continuing powers of attorney take effect the moment they are issued. In some models, the lawyer is initially authorised to perform minor legal acts. Only after the mental incapacity of the grantor (e.g. where a person with dementia has been diagnosed by a medical expert), the lawyer is fully authorised

to represent all interests described in the power of attorney.

There is no specific legislation regarding continuing powers of attorney and the supervision of the power of attorney. Notaries strongly advise the grantor to include some form of control in the power of attorney, but this is not mandatory. In a number of cases, the lawyer is supervised by another family member. In the event of misuse or abuse of the power by the lawyer, the court may impose an adult guardianship measure.

### **North Macedonia**

People who have power of attorney (closer in nature to guardianship) are supported by the Centre of Social Care and regulated by the family law. A person cannot hold a power of attorney if they have had their parental rights revoked or if they themselves have lost their legal capacity. There is only one attorney for all decisions and this person will be supported by social services in the exercise of their role. If the person living with dementia is institutionalised and has no attorney, social services can appoint an attorney. An attorney cannot represent the person in family matters or family conflicts. In those cases, a new attorney is appointed by Social Services.

Attorneys must get permission from social services in making some of the decisions (e.g. selling property). If their property needs to be assessed, this is done by a commission formed by Social Services, and the person living with dementia can be present.

The attorney is obliged to submit a written report to social services once a year (or more often if requested). If any concerns are raised about the work of the attorney, social services have a procedure to investigate this.

### **Norway**

Anyone aged 18 or older with the ability to understand the significance of a power of attorney may appoint an attorney. Enduring powers of attorney may include decisions regarding financial, personal and health care matters. An enduring power of attorney takes effect when the principal is no longer capable of managing their own interests in matters covered by the enduring power of attorney. In many cases a medical certificate

stating that the principal is no longer capable of managing their own interests is necessary.

There is often a need to obtain confirmation from the County Governor that an enduring power of attorney has become effective. However, an enduring power of attorney will also take effect and become effective without confirmation, as long as it has been validly established and the principal is no longer capable of managing their own interests due to severe health impairment.

There is no public oversight of powers of attorney and there are no special provisions in place to prevent misuse. In case of misuse, criminal law would apply.

### **Poland**

In order to be able to empower another individual to take actions, the one granting their legal rights must have full mental capacities and be at least 18 years old. The granter and the authorised person must come in front of a notary to sign the document. The power of attorney can be effective for an indefinite or specified period of time, with time-limited powers typically used for certain tasks like selling or buying property, making payments, submitting documents or any other actions as instructed by the grantor.

Within the scope of their powers, Polish notaries act as persons of public trust, enjoying the protection of public officers. In accordance with the Polish Notaries Law Act, actions performed by a notary in compliance with law are acknowledged as official documents. When performing the notarial actions, notaries are obliged to safeguard the rights and legitimate interests both of the parties to the transaction and of persons in respect of whom a respective notarial action may entail legal effects.

Notaries are under a duty to provide parties a transaction with explanations concerning the latter, and authentic instruments and documents must be prepared in a comprehensible and transparent manner. Notaries are not allowed to perform a notarial action in cases where there are doubts as to a party's capacity to take decisions or to express their intentions freely.

There is no specific monitoring system for powers of attorney. The Polish National Council of Notaries maintains a digital system of the statistical registers and registers containing data of some types of notarial actions, which allows for data exchanges with some external institutions. The consequences of misusing power of attorney can be severe. If someone is found guilty of doing so, they can face criminal charges and be sentenced to prison for up to three years.

### **Portugal**

It is possible to appoint an attorney and give them the powers to act on the person's behalf in different areas including managing or disposal of property, financial matters, civil contracts, decisions about care and health issues, health information etc. The power of attorney remains in force even when the person loses capacity. Any possible guardianship decisions must bear in mind any power of attorney or other advance decision made by the person, and shapes how it will be articulated in guardianship powers.

### **Spain**

Powers of attorney allow one person (attorney-in-fact) the power to act on behalf of another (principal) in specific matters or in general. These powers of attorney are used to authorise someone to act on behalf of the principal when the principal is unable or is unwilling to do so. The principal must be of legal age and have the capacity to understand the nature and implications of the power of attorney that they are granting and do so in a voluntary and conscious way – the notary is responsible for confirming this.

The principal must appear before a public notary to express their will to grant power to a specific person and detail the powers and scope. The notary will advise the principal and ensure that they fully understand the implications of the granting these powers.

The notary will draft the power of attorney in line with the wishes of the person and current legal regulations. The document identifies who is the principal, who is the attorney-in-fact and the specific powers granted (as well as whether it is temporary or indefinite). Only the powers outlined in the document can be performed by the attorney-in-fact.

Once signed by the principal and stamped, dated and signed by the notary, it is recorded in a public register (register of powers of attorney of the chamber of notaries), making it possible for third parties to consult whether a person has been granted powers of attorney and their powers.

Powers of attorney can be revoked at any time by the principal if they have capacity to do so, including if they believe the powers are being misused. The principal or their legal representatives can take legal action against the attorney-in-fact, including through civil or criminal proceedings, depending on severity, as outlined in Law 8/2021.

### **Sweden**

People with dementia can give enduring power of attorney to close relatives while their cognitive abilities still permit them to understand the situation. Where a person hasn't specified who shall be given enduring power of attorney and is no longer able to manage their own personal matters, a court can appoint a legal guardian, as well as limiting the person's ability to enter legally binding contracts on their own.

Powers of attorney and guardianships are monitored by a board in the municipal government (överförmyndarnämnden). They can replace legal guardians who are deemed unsuited for their position, and petition the court to appoint a guardian in cases where it is deemed necessary.

### **Switzerland**

Submitted to the regulations of adult protection. There are no special monitoring other than for all legal fields.

### **Turkey**

People with dementia can give power of attorney through their guardians. Power of attorney may be granted by the guardian so that they can use it in matters that require litigation.

If the power of attorney is misused, it is ensured that the person who abuses the authority is prosecuted and punished under the Turkish Criminal Code, as part of which, the material and non-pecuniary damage that has occurred must be legally compensated.

### **Ukraine**

Powers of attorney are granted on the basis of agency agreement. Powers of attorney last from the moment the agreement is signed (in simple written form), notarised and entered into the state register. A legally capable person can grant the powers of attorney to third parties to authorise any acts (except for personal matters such as entering into marriage, changing legal name etc).

A person with dementia, if not found lacking legal capacity by the court, can grant powers of attorney to a person or persons to make decisions regarding their movable and immovable assets including finances, to make decisions about treatment, appointing guardians or selecting live-in or treatment facilities.

There is no monitoring of powers of attorney, however, misuse is subject of criminal law if discovered by relatives, care and protection services, notaries etc.

### **United Kingdom – Scotland**

An adult aged 16 or over in Scotland can grant continuing powers of attorney for financial or property matters, or a welfare attorney for matters relating to care, support and treatment. These can be granted alone or together in one document.

The adult must be able to understand the implications of granting powers of attorney and there should be a certificate confirming that the adult has capacity to do so. Where a solicitor helps a person draw up powers of attorney, they need to certify that they are satisfied that the person has capacity and that they are not under any undue influence. Where required, they may seek the opinion of a medical practitioner regarding the person's capacity to sign a power of attorney. Continuing Powers of Attorney must be registered with the Office of Public Guardian before they can be used. Welfare powers of attorney can only be used when the adult no longer has capacity in relation to the welfare powers that have been granted.

Any attorney must act according to the principles of the Adults with Incapacity Act and only where the adult needs to be supported to make the specific decisions to which the powers of attorney relate. The Adults with Incapacity (Scotland) Act 2000 provides a

framework for safeguarding the welfare and managing the finances of adults (people aged 16 or over) who lack capacity due to mental illness, learning disability, dementia or a related condition, or an inability to communicate.

Powers of Attorney are not monitored, however, under certain circumstances (as described below) a sheriff can require an attorney to be supervised.

Under the 2000 Act, local authorities have a duty investigate any complaint about how a welfare attorney is exercising the powers granted to them, or any circumstances where the persons welfare is

at risk. Under the Adult Support and Protection Act 2007, local authorities have a duty and significant powers to investigate circumstances where an “adult at risk” as defined by the Act is at risk of harm. Harm is not defined includes any harm such as financial, physical, psychological harm because of deliberate acts, omissions or neglect.

Where there are concerns, a local authority or any interested party can apply to a Sheriff for direction. A Sheriff has powers under the 2000 Act to remove all or some of an attorney’s powers or require an attorney to be supervised.



## 10. Substitute decision making and/or supported decision making

Where the granting of powers of attorney are not possible or not suitable, other forms of decision-making may be articulated in law or in the practice of providing support for the person. A common and established form of this is a guardianship order, usually granted by a court, in which a person is granted certain powers in order to carry out specific functions. However, as noted in previous sections, this form of decision-making is considered by the Committee of the UNCRPD as incompatible with the Conventions on rights, as the decisions as to who represents the person, the scope of powers etc. are made by the court, with the guardian making decisions on behalf of the individual, sometimes on the principle of “best interests”.

As disability policy in countries has progressed in recent years, supported decision-making has emerged as a way to ensure that people are able to exercise capacity and autonomy as far as possible by making it easier for them to do so.

### Austria

There are various forms of representation which are set out by the 2<sup>nd</sup> Adult Protection Act. The aim is to give the persons concerned the greatest possible autonomy. The person concerned still has the last word in all decisions. If it is somehow apparent that a person concerned does not want a certain action, this is to be accepted. The same applies if a recognisable will of the person concerned contradicts the decision of the person representing them.

### Belgium

According to the SPF (Service Public Fédéral), the intervention of the justice of the peace is necessary when a person is placed under administration. They decide whether the protected person needs assistance or representation.

Assistance means that the protected person acts without autonomy, and representation means that the administrator acts in the protected person’s place. However, the administrator must involve the protected person and inform them of these acts. The principle of proportionality is defined as the adequacy between the objective sought and the decision taken, meaning that one must use proportional means to solve a problem. Therefore, when making a decision, it should be done in such a way as to affect the person’s freedom as little as possible to achieve the specific objective.

### Bulgaria

In Bulgaria there is only full and partial guardianship and no other forms of decision making. There is no legislative framework for supported decision making. The court determines whether there should be full or partial guardianship for actions of the individual.

### Czech Republic

There are three levels of regulation of decision-making Under Act No. 89/2012 Coll.. The Civil Code provides for assistance in decision-making (nápomoc při rozhodování, Section 45 et seq.) and representation by a household member (zastoupení členem domácnosti, Section 49 et seq.) as the milder forms of protection measures for adults with loss of capacity.

The limitation of legal capacity (in Section 55 ff.) is only envisaged in cases where the more moderate measures are not sufficient. Legal capacity may be limited exclusively by a court, which is obliged to appoint a guardian (opatrovník).

Assistance in decision-making offers a way of protecting people with a slight disability and applies where it is not necessary to take decisions on behalf of the person concerned such as by a legal guardian but where the person requires assistance in making decisions. The person providing such assistance does not act in place of the person, but rather supports



them by providing the necessary information and advice. The assistance agreement enters into force as soon as it has been approved by a court. The assistance may be remunerated, but any such remuneration must be reasonable.

The representation by a household member applies to adults who do not have another legal representative and who are not capable, because of a mental disorder, of acting independently. The legal representative must clearly explain the nature and consequences of the representation to the person. If the person does not provide consent, the representation is invalid. To refuse the representation, the person must simply be capable of expressing their wishes.

To become effective, the representation must have been approved by a court. Before ruling, the court must take the necessary measures to ascertain the wishes of the person represented and may rely on a method chosen by the person concerned. The powers of representation cover only routine (ordinary) acts, depending on the usual (normal) conditions of life of the person represented. The legal representative is not entitled to give their consent to acts that might permanently impair the person's mental or physical integrity.

Courts can also impose guardianship, with or without restriction of legal capacity, if the person's state of health causes difficulties in the management of their property or in the defence of their rights. It is also possible to provide a guardian only to manage the estate, under section 469 of Act No. 89/2012 Coll.

### Denmark

The Danish Guardianship Act requires that if a person is unable to manage their personal and/or financial affairs, a guardian may be appointed. An ordinary guardianship does not per se deprive the person under guardianship of their legal capacity. The guardian acts only on behalf of the person regarding the matters agreed upon in the guardianship. The Agency of Family Law appoints a guardian. There are three types of guardianship: Financial guardianship, Personal guardianship and co-guardianship.

It is recommended that people establish a future power of attorney while still healthy, to ensure they can decide for themselves who will look after their financial and personal interests if they are no longer able to do so. The future power of attorney is created electronically and signed in front of a notary. For a person with dementia who cannot handle digital documents, the future power of attorney can be completed on paper and signed before an employee at the Agency of Family Law.

The principle of proportionality is defined by the fact that the use of compulsion and force must be proportionate to what is to be achieved. Specifically, the principle of least intrusive measure is contained within the Act as a legal principle to be applied to persons under guardianship.

### Estonia

The substituted judgment model gives the legal guardian the right to decide instead of the person with disabilities. The guardian must consider the expressed wishes and values of the person under guardianship and always act in the best interests of the person under guardianship.

Guardianship is assigned to perform all or certain tasks, depending on the person's mental health. A person may be deprived of all rights, however, the right to make small financial transactions is often preserved. It is common that that the persons with limited legal capacity are not involved in decision making processes on their living conditions, and the opinion of social field professionals and staff of care facilities are more commonly used.

In relation to proportionality, the Family Law Act section 203 states:

1. *If an adult person is permanently unable to understand or direct his or her actions due to mental illness, mental disability or other mental disorder, a court shall appoint a guardian to him or her on the basis of an application of the person, his or her parent, spouse or adult child or rural municipality or city government or on its own initiative.*
2. *A guardian shall be appointed only for the performance of the functions for which guardianship is required.*

*Guardianship is not required if the interests of an adult can be protected by granting authorisation and through family members or other assistants. Upon establishment of guardianship, a court shall assess the person's capability to understand the legal consequences of contraction of marriage, acknowledgement of paternity and other transactions concerning family law.*

3. *A guardian's duties may include exercise of a ward's rights against third persons.*
4. *A court shall verify at least once every five years whether the continuation of guardianship over a ward is necessary for the protection of the interests of the ward and whether grounds exist for extension or restriction of the duties of the guardian by making a respective ruling.*

### **Finland**

A person can apply for a guardian when, at the age of 18, they are unable to manage financial affairs due to an illness, deteriorated state of health or other similar reason. It is recommended only where personal affairs cannot be managed using alternatives to guardianship (e.g. power of attorney). Guardians may manage:

- Property and financial affairs on an ongoing basis
- Property and financial affairs only for a certain period
- An individual task only, such as the sale of a property or the distribution of inheritance.

Even if a guardian is appointed to manage the client's property and financial affairs, they must also make sure that their client is properly cared for and arrange for care. If ordinary guardianship is not sufficient to ensure, for example, appropriate care and housing, the guardian may also be appointed to represent their client in matters relating to personal affairs, such as deciding on their care. This is only possible where the person is not able to understand the matters in question.

A guardian can be a private person, such as a relative or another person who is close to the person in need of guardianship, where they give their consent to take on the task are deemed to be suitable for the task. The guardian may also be a public guardian whose full-time job is to manage the financial affairs of several different persons.

### **France**

The various legal protection measures (safeguard of justice, curatorship and guardianship) are put in place in the interest of the person, according to their degree of incapacity assessed by the judge on the basis of a detailed medical certificate drawn up by an approved doctor, and following the hearing of the person concerned, if their state of health allows it. Thus, protective legal measures must be reserved for people suffering from an impairment of their personal faculties, especially mental. Protective measures must also be adapted and tailored to the person's situation.

While the person to be protected can request the establishment of a protective measure themselves, this is often done by someone close to them (spouse, PACS partner, cohabiting partner, family member or very close person), though can also originate from the public prosecutor. All requests require the establishment of a file, which must be accompanied by a detailed medical certificate. Three legal protection measures can be applied depending on the case.

- The "safeguard of justice", which does not imply legal incapacity, can be pronounced during the proceedings by the guardianship judge, pending their final judgment. It is then referred to as a "provisional justice safeguard" or "judicial safeguard". It constitutes the final decision rendered by the guardianship judge and therefore represents the mildest of judicial protection measures, referred to as "autonomous judicial safeguard".
- "Curatorship" enables the protected person to be assisted in most acts of civil life. This measure concerns people who benefit from a certain autonomy but who nevertheless need to be assisted or monitored on an ongoing basis in important acts such as those relating to inheritance. In cases where the curatorship is reinforced, the curator (the person in charge) collects the income of the person and pays expenses.
- "Guardianship" results in legal incapacity and is the most comprehensive measure. The guardian represents the person in all acts of civil life, with rare exceptions, and performs administrative acts alone. The family council, or the judge, authorises them to carry out acts that affect the person's patrimony.

A “future protection mandate” allows any adult person to organise in advance the future management of their property and their person (health, well-being, dependency etc.), in anticipation of the day when they may no longer be capable of protecting their own interests alone. This mandate does not lead to legal incapacity per se and can be done by a person living with Alzheimer’s disease, providing they may conscientiously entrust their interests to a loved one.

The mandate for future protection is a legal act that cannot be reduced to a standard form or notarial act and must consider multiple possible needs and correspond to the specific situation of each person. To be activated, the agent must provide a detailed medical certificate of incapacity to the registry of the guardianship judge. The mandates do not allow for control of the management accounts unless the mandate provides for entrusting this control to an accounting firm or chartered accountants. In the event of a fault committed by the agent, anyone can alert the guardianship judge, who can then revoke the mandate.

### Germany

Guardianship in Germany is set out in section 1814 of the Civil Code, which defines guardianship and states that:

1. If an adult is legally unable to manage his or her affairs in whole or in part, and this is due to illness or disability, the guardianship court will appoint a legal guardian (guardian) for them.
2. A guardian may not be appointed against the free will of the adult.
3. A supervisor may only be appointed if it is deemed necessary. In particular, where the appointment of a guardian is not necessary as far as the affairs of the adult are concerned:
  - It can equally be provided by an authorized representative, or
  - It can be carried out through other assistance for which no legal representative is appointed, in particular through support based on social rights or other regulations.
4. A guardian is appointed at the request of the adult or ex officio. If the adult cannot manage his or her affairs simply due to a physical illness or disability, a guardian may only be appointed at the request

of the adult, unless the adult cannot express his or her wishes.

5. A guardian can also be appointed for a minor who has reached the age of 17 if it can be assumed that the appointment of a guardian will be necessary upon reaching adulthood. The appointment of the guardian only becomes effective when the child comes of age.

Proportionality exists insofar as the person is subject to proxy measures only in those areas that they can no longer manage themselves. Depending on their abilities, there may be involvement of the legal guardian. The persons concerned thus retain much more self-determination than in the case of the former guardianship. Legal guardians are obligated to consider the wishes and needs of the person being cared for as far as possible.

### Hungary

The Law of Supported Decision-making, CLV of 2013 regulates the limiting of capacity to act.

### Ireland

The Assisted Decision-Making (Capacity) Act 2015 has 3 different types of decision supports depending on how much help a person needs to make certain decisions. A person can also plan for a time in the future when they might not be able to make certain decisions for or by themselves. The DSS calls all the people who help in these different ways ‘decision supporters’.

1. 1. Decision-making assistant: The person makes their own decision with support from their decision-making assistant. Their decision-making assistant helps them to access and understand information and to communicate their decision.
2. Co-decision-making agreement: the person makes specified decisions jointly with a co-decision-maker.
3. Decision-making representation order: the court appoints a decision-making representative to make certain decisions on the person’s behalf.

The Assisted Decision-Making (Capacity) Act 2015 provides that any person with a genuine interest in the welfare of another person can apply to the Circuit Court for a declaration as to their capacity to make specified decisions. This is called a Part 5 application.

The court can make a decision-making representation order which sets out the specific decisions that the appointed decision-making representative can make. There are express exclusions, so that a decision-making representative is never authorised to make decisions about life-sustaining treatment or to prohibit a person from having contact with the relevant person. There are requirements to limit the making of gifts.

The representative must also ascertain the relevant person's will and preferences and assist the relevant person in communicating such will and preferences. The decision-making representative is supervised by the DSS and is required to keep accounts and records and submit annual reports.

### **Italy**

The “amministrazione di sostegno” (support administration) is an adaptable and flexible tool for each individual and particular situation of hardship and will be adapted from time to time to the different needs of the person. However, it is the judge who establishes whether the function of the support administrator will be assistance or substitute, as well as establishing which acts to be performed by the person alone, which acts to be performed by the person with the assistance of the supporter and which acts to be performed by the supporter alone.

The primary task of the “amministratore di sostegno” (support administrator) is to help and the person, whilst always keeping in mind the will, needs, interests and aspirations of the person. All actions taken should be with the least possible limitation to the person. The law establishing the support administration very clearly outlines the central humanity of person, including their dignity, which are the basis for the interpretation of norms.

### **Luxembourg**

Legislation has three systems of protection for adults, including people with dementia, which seek to serve as a protection against malicious third parties, as well as a tool of administrative and financial requirements. The three safeguards are:

- Judicial guardianship (“sauvegarde de justice”): this is usually of limited duration and often serves

as a transitional measure until legal counsel or guardianship is established.

- Curatorship (partial guardianship or “curatelle”): this applies to persons whose mental capacity is so severely impaired that they need the assistance of legal aid in the conduct of civil life.
- Guardianship (full guardianship or “tutelle”): this applies to persons who are no longer able to express themselves and therefore have to be represented by a guardian.

The guardianship judge will decide whether protection is necessary or not, as well as which level of safeguard to apply. As a rule, the judge gives preference to a member of the family to act as an assistant or guardian. If no person is available or reliable, the judge may appoint an independent third party, such as a lawyer or a specialised association.

### **Malta**

Application for the appointment of a guardian or joint guardianship is made to and decided by the Guardianship Board.

It is also possible for an adult with a mental disorder or other condition which renders him incapable of managing his own affairs to be interdicted or incapacitated from performing certain actions by filing out an application to the Court of Voluntary Jurisdiction, where a curator will be appointed. The curator of an interdicted person administers the patrimony of the interdicted person in its entirety, whilst the curator of an incapacitated person merely assists in the administration of assets. Thus, throughout incapacitation, the person retains control of their assets.

Guardianship Orders are issued by the Guardianship Board and the Court of Voluntary Jurisdiction is notified by the Order, with each order issued differing depending on the specific circumstances of each case.

### **Netherlands**

Substitute decision-making is generally considered a last resort, however, this position is not explicitly enshrined in legislation. The three adult guardianship measures exist: full guardianship, financial guardianship and personal guardianship, and all result

in the appointment of one or two representatives and the *ex lege* deprivation or restriction of the adult's legal capacity.

The person under guardianship can independently perform legal acts with the permission of their representative or sometimes of the court. In the case of full or personal guardianship, the *ex lege* infringement of legal capacity can be lifted if another law has different rules on this point (Articles 1:381(2) and 453(1) DCC).

An exception to the impairment of legal capacity occurs in care situations. Health legislation, including mental health care legislation, applies the principle that an adult client or patient can decide for himself if he is mentally capable of making the decision, even in the case of a guardianship measure. The primary role of full guardians and personal guardians in care situations is therefore to advise and support the adult in making their own decisions. Only if the adult is unable to make a decision despite support from their guardian may the guardian decide for them.

This approach regarding supported and substitute decision making is not explicitly articulated in adult guardianship provisions, rather the preference for supported decision stems from the interplay between family law and health law. However, it is absent in the legislation on adult guardianship in the field of finance and property, though one of the requirements for professional guardians as stated in a Quality Requirements Decree is to ensure the self-sufficiency of the adults as much as possible.

Shared decision making is promoted by lawyers and medical professionals. The Medical Treatment Contract Act (WGBO) was amended a couple of years ago by introducing the obligation for medical professionals to open a dialogue with the patient. When discussing options for treatment or therapy, the professional no longer can limit themselves by informing the patient of the pros and cons of the treatment and await consent. The idea behind the new article 7:448,3 DCC is to initiate shared decision-making. The professional acquaints themselves with the patient's situation and needs and invites the patient to ask questions

People with dementia can express their wishes and preferences for a possible later period of mental incapacity in different ways e.g. by a statement included in a continuing power of attorney. In legislation, there are two laws that formulate the possibility of an advance directive. The Medical Treatment Contract Act [WGBO] offers the possibility for patients to draw up an advance directive on health matters in which they withhold their consent for treatment in a future situation in which they are mentally incapable to make a decision about this (article 7:450 (3) DCC). The situation must be well described. The care provider may deviate from this advance directive if he has good reasons to do so. Another form of advance directive can be found in the Euthanasia Act, whereby the patient does not withhold his consent but writes down his wish to undergo euthanasia if a number of conditions are met and he cannot formulate an actual wish for euthanasia at that time due to mental incapacity (Article 2 (2) Euthanasia Act).

The principles of subsidiarity and proportionality are laid down in the DCC. When dealing with a request for plenary guardianship, the court must determine whether a more appropriate and less far-reaching remedy would suffice. The court is authorised to reject a request for a plenary guardianship, instead ordering a financial or personal guardianship (Articles 1:378(1), 432(3) and 451(3) DCC).

In practice, requests for financial guardianship are often rejected when the person is still capable of issuing a continuing power of attorney, and requests for personal guardianship are rejected when the person is a partner or close relative and *ex lege* authorized to represent the mentally incapable person.

### North Macedonia

Full guardianship systems are in place under legislation, however, whilst there are advanced directives, these are not legally binding. When a person's capacity is questioned, a capacity assessment may be required, which can yield one of the following outcomes:

- Partial incapacity: children aged 14-18, for example, are deemed to have partial incapacity, however, the court can also decide that some adults, due to different reasons have partial incapacity to

make decisions. In this case, the person can make decisions on their own, but they must be approved by their guardian to be legally binding.

- Full incapacity: all decisions are made by the guardian and the person has no legal agency.

In some instances, people who were deemed to have full incapacity can be reassessed as having partial incapacity.

### **Norway**

The Guardianship Act acknowledges the need for substitute decision-making when individuals lack decision-making capacity. In such cases, a personal guardian or representative may be appointed to make decisions on behalf of the individual within the areas of need where decision-making capacity is lacking. Furthermore, it encourages measures to enhance the person's ability to make decisions, such as providing appropriate information, communication, support and assistance, with the aim of enabling individuals to exercise their decision-making capacity to the fullest extent possible.

This is also reflected in the Patients' and Service Users' Rights Act, which emphasises the importance of involving patients and, if appropriate, carers in healthcare decisions. It stipulates that healthcare professionals should provide patients with relevant information, discuss treatment options and take the patient's preferences and values into account when making decisions about their care. Shared decision-making promotes a collaborative approach between healthcare providers and patients, ensuring that decisions align with the patient's wishes and goals. Carers may also be involved in these decisions. The overarching principle is to ensure that decisions are made in the person's best interest, taking into account their will and preferences as much as possible.

Ongoing efforts are being made in Norway to develop legal frameworks and guidelines that further support substitute, supported and shared decision making. These efforts aim to enhance individual autonomy and promote the rights of individuals in various decision-making contexts.

A guardianship is a voluntary arrangement and does not normally include the deprivation of legal capacity. Adults can either establish voluntary guardianship without deprivation of legal capacity or establish guardianship with full or partial deprivation of legal capacity.

In cases of guardianship with deprivation of legal capacity, the following conditions must be present:

1. Requirement for a medical condition (diagnostic requirement)
2. The person is unable to take care of their own interests
3. There must be a need for a guardian based on the overall situation
4. There must be a causal relationship between the person's condition and their inability to take care of their own interests.

The person with assistance needs can be deprived of legal capacity in financial and/or personal matters if it is deemed necessary in order to prevent them from endangering their assets or other financial interests, or if they are being exploited financially in an undue manner. The deprivation of legal capacity may be limited to specific aspects or specific transactions. A person may be deprived of their legal capacity in specific personal matters if there is a significant risk that they will act in a manner that would substantially harm their interests. However, in personal matters it is not possible to fully deprive a person of legal capacity. A person can never be fully deprived of legal capacity in particularly personal matters. Creating or revoking a will, getting married, or consenting to coercion are examples of such particularly personal matters.

An enduring power of attorney (*fremtidsfullmakt*) is a civil law alternative to a guardianship and may fully or partially replace the function of a guardianship. Relatives also have the right to represent a family member with dementia if the person is no longer able to manage their financial interests. The relative has the right, on behalf of the family member, to make financial transactions concerning the family member's residence and daily maintenance. The relative also has the right to ensure the payment of public taxes and fees and obligations arising from valid loan

agreements entered into by the family member. The right of representation by relatives does not apply if a guardian has been appointed or if the matter is covered by an enduring power of attorney.

The principle of minimal intervention guides guardianship legislation, meaning that guardianship cannot be established in cases where a person's need for assistance can be met through less intrusive measures than guardianship. The proportionality principle is observed, and the decision of full or partial legal capacity deprivation has to be adapted to the person's need for assistance to the greatest extent possible.

### Poland

The government has begun working on the implementation a new legal instrument of supported decision-making which would replace incapacity procedures; however, current legislative measures rely on substitute decision-making, whilst advance directives do not exist in the legal system. The idea of supported decision making has been often described as necessary by the Human Rights Commissioner, who believes the incapacitation of persons with intellectual disabilities or mental disorders is a sign of discrimination and unequal treatment.

According to Article 13, Section 2 of the Polish Civil Code, a fully incapacitated person is provided with a guardian, if the person is not still under a parental authority. Whereas, for the person partially incapacitated, according to Article 16, Section 2 of the Civil Code, a curator is established.

The main role of the guardian is to manage affairs of fully incapacitated person and act on their behalf. The completely incapacitated person does not have a right to undertake legal actions, with exceptions for everyday contracts in minor issues of daily life if they are not harmful for the incapacitated person. However, the person cannot enter into marriage nor make a will.

The main role of the curator is to support or assist the partially incapacitated person in their affairs. Generally, the partially incapacitated person may undertake legal actions, but these actions need to be approved by their curator, with the exception of minor issues in daily life, decisions concerning their job, or concerning

earnings obtained from work. Partially incapacitated persons are allowed to enter into marriage but cannot make a will.

Incapacitation is an institution of the civil law; however, different areas of law address this including Article 62 Section 2 of the Constitution, which outlines that incapacitated persons do not have electoral rights, the right to participate in a referendum, the right of access to public service or the right to set up an association or political party.

Each person declared partially or completely incapacitated is being placed under the protective system established by the Polish law. Once the decision on incapacitation is final and valid, the Regional Court is obliged to inform (ex officio) the District Court (the Guardianship Court) about its decision. The District Court then establishes (ex officio) a guardian or a curator for that person.

The decision of the Regional Court declaring an incapacitation may be a subject to appeal to the Court of Appeal. An appeal can be lodged by participants of the proceedings such as their spouse, their statutory representative or a public prosecutor.

General rules of civil proceedings are applied to appeal procedures. The Family and Guardianship Code recommends appointing the closest family member of the incapacitated person as a guardian or a curator. If there is no such person, the Guardianship Court asks the representatives of social service or non-governmental organisations protecting the rights of minors to indicate a proper candidate (art. 149(3) and art. 175 of the Family and Guardianship Code).

The test of proportionality is contained in Art.31 of the Polish Constitution. It is construed as the sum of three component principles: of usefulness, of necessity and of prohibition against excessive interference. However, despite the existence of two levels of incapacitation, courts declare complete/full incapacitation in an overwhelming majority of cases.

### Portugal

The current guardianship legal framework is based on the principles of autonomy and on the least restrictive

measures, therefore promoting supported and shared decision-making, with substitute decision-making being the exception. Greater relevance is also given to advance decisions on health (living will and healthcare proxy). For example, the person may choose in advance who will help him to make decisions or to act on his behalf (“acompanhante” or the guardian) and it is possible to choose more than one person.

Additionally, the person (when still capable) may make an agreement (“contrato de mandato com vista ao acompanhamento”) with someone, family member or not, to make decision on his behalf if and when the person loses capacity. These decisions may be on very different issues including managing or selling real state, managing bank accounts, choosing the place to live and/or care decisions. In the future, when court measures are declared, this agreement will be considered and may influence the decision to choose the “acompanhante”.

The court decision which declares the measures (medidas de acompanhamento) will also have to take in account whether the person had made a living will or a health care proxy, and to assure a good articulation among all stakeholders including the “acompanhante(s)” and the health care proxy.

There is a recent legal framework for persons with diminished capacity (“Regime do Maior Acompanhado”) in line with the UNCRPD which came into force on the 10 February 2019. Since then, people have become much more aware of the need to decide in advance and to start the judicial procedure to ask the court to enact the measures needed to help the persons who are not able to exercise their rights or fulfil their duties. Measures are enacted with the intention of being the least restrictive possible to respect the person’s autonomy.

For instance, if a person with dementia starts to experience difficulties in dealing with complex decisions, including finances, but is still capable of taking personal decisions such as choosing the place to live, making an advance directive or a will, it is possible for the person to ask the court to appoint me a person (“acompanhante”) to help me taking decisions on my money, real state or savings.

### **Spain**

According to Law 8/2021 of 2 June, which reforms civil and procedural legislation to support people with disabilities in the exercise of their legal capacity, there are different figures of representation and support.

New law aims to promote and ensure the greatest possible autonomy of the person with disability. This involves determining the specific need or needs of the person at any time, so that the supports that are offered must be periodically revised. For instance, at times, they may need help accessing a loan, managing their money, or making decisions about their health.

There are several ways of providing support to the person with disability:

- Informal support: de facto guardian.
- Formal and voluntary support: powers of attorney, mandates, and notary deeds.
- Judicial support: curatorship and judicial defender.

Law 8/2021, which came into effect on September 2021 has completely modified the previous system based on the incapacitation of the person (or modification of capacity), removing the former figure of guardianship, as well as extended or rehabilitated parental authority and prodigality.

No one can be incapacitated anymore. Now, the law establishes a system of supports to help people with disabilities in different ways and to different degrees. The idea is not to substitute the person, nor to represent them (since the guardian was their representative at all levels), but to provide them with support in the specific ways they need it, respecting their will, wishes, and preferences. The previous system was representative. substitutive of the person, and was based on protecting the person’s interest without taking the person into account.

The person can go to a notary to establish their own support measures or designate their guardian. Indeed, because they are established by the person themselves as “voluntary measures” and because they are made before a notary, they are said to be formal. The voluntary measures can be as extensive as the person wants and requires and establish the



parameters that they consider appropriate.

Law 8/2021 of 2 June, which reforms civil and procedural legislation to support people with disabilities in the exercise of their legal capacity is based on the law of proportionality and necessity.

People who provide support must act in accordance with the will, wishes and preferences of the person requiring the support. They shall also ensure that the person with disability can develop their own making-decision process, reporting to them, helping them understand, reason and facilitate the expression of their preferences. They also will encourage the person with disability to exercise their legal capacity with less support in the future.

In exceptional cases, when, despite considerable effort, it is not possible to determine the will, wishes and preferences of the person, support measures may include representative functions. In this case, the exercise of these functions must take into account the life course of the person with a disability, his or her beliefs and values, as well as the factors that the person would have taken into consideration in order to make the decision that they would have made had they not required representation.

The judicial authority may dictate the safeguards that it considers appropriate to ensure that the exercise of support measures complies with the criteria resulting of this provision and, particularly, meet the will, wishes and preferences of the person who requires them.

### Sweden

There are several laws that direct healthcare and social services to regard the will of the patient when planning care or treatment. Guardians can only assist the patient and not make decisions for the patient in health care matters.

There are different levels of guardianship. Under a less strict guardianship the person can still enter legally binding contracts.

There are two types of legal representatives (guardianships) for adults that affect the legal capacity. One is more intrusive than the other. Hence, there are

two different definitions of vulnerable adults, or rather two different intensities of vulnerable adult.

A “good man” (in Swedish: god man) is the less intrusive judiciary protection and requires the consent of the adult in need of help both before being appointed and before every legal action in their name (Ch. 11 Sec. 4). A good man can, however, be appointed even if the adult in need cannot give their consent. To be assigned a good man, the person must need help to safeguard their rights, manage their assets, or care for themselves due to illness, mental disorder, frailty or similar conditions. The least encroaching measures must be explored e.g. where a power of attorney may be sufficient.

The more intrusive, administrator (in Swedish: förvaltare), requires for the adult to not only be in the situation described above and in need of help but to be completely incapable of doing so (Ch. 11 Sec. 7). An administrator can be assigned by the court without consent, and the commitment is custom-made to suit the individual’s particular needs. Just like with the good man, the least encroaching measures must be explored first and the protection should end or decrease as soon as it is deemed excessive.

Continuing Powers of Attorney and ex lege representation can be used under the same condition required to appoint an administrator (§ 1; Ch. 17 Sec. 1).

The court is always obligated to consider if an action that interferes to a lesser degree in a person’s life can still achieve the necessary protection and results.

### Switzerland

In Switzerland, the legislation on adult protection provides for advance care instruments in legal or medical matters. For legal matters in general, a person with capacity to act may instruct a natural person or legal entity to take responsibility for their personal care or the management of their assets or to act as their legal agent in the event that they are no longer capable of judgement. They must define the tasks that are to be assigned and may issue instructions on how these tasks are to be fulfilled.

With regard to medical matters, a person may specify in a patient decree which medical procedures they agree or do not agree to in the event that they are no longer capable of judgement. The person may also designate a natural person who, in the event that they are no longer capable of judgement should discuss the medical procedures with the attending doctor and decide on their behalf. They may issue instructions to this person (Swiss Civil Code, Art. 370 et seqq.).

The adult protection authority establishes a deputyship if an adult is wholly or partially unable to manage their own affairs and has not appointed a representative. The adult protection authority defines the scope of the deputyship's responsibilities according to the needs of the client. «Light» forms of guardianship aim at supportive decision-making in which guardians act as coaches for the person concerned. The scope of responsibilities relates to personal care, the management of their assets or legal matters. Without the consent of the client, the deputy may only open their post or enter their residence if the adult protection authority has expressly granted the power to do so (Swiss Civil Code, art. 390 et seqq.).

On a practical level however, we observe that many people still don't make use of the legal possibilities to express their will and wishes as long as they are still capable of judgement (advance care directive, patient decree). The implementation of these (complex) instruments depends on continuous efforts in terms of information and awareness-raising measures. In Switzerland, this is considered foremost a task of civil society (closer to the people concerned), but public funds could/should be increased in order to assure a better outcome.

Swiss Civil Code, Art. 393 et seqq. clarifies the following types of deputyships:

- Assistance deputyship: established with the consent of the person in need if they need assistance in order to deal with certain matters. The assistance deputyship does not limit the client's capacity to act.
- Representative deputyship: established if the person in need is unable to deal with certain matters and therefore must be represented. The adult protection

authority may limit the capacity of the client to act accordingly. Even if their capacity to act has not been limited, the client is bound by the acts of the deputy.

- Asset management: if the adult protection authority establishes a representative deputyship to manage assets, it shall specify the assets to be managed by the deputy. It may make up all or part of the income, all or part of the capital or all or part of the income and capital subject to the deputy's management. The management powers also cover savings from the managed income or the revenue from the managed capital unless the adult protection authority provides otherwise. Without limiting the client's capacity to act, the adult protection authority may prohibit them from accessing individual assets. If the adult protection authority prohibits the client from disposing of heritable property, it must arrange for a note to be made in the land register.
- Advisory deputyship: established if the client requires, for their own protection, that certain acts be made subject to the consent of the deputy. The client's capacity to act shall thus be limited accordingly by law.

General deputyship: established if a person, in particular due to permanent loss of capacity of judgement, is in particular need. It covers all aspects of personal care, management of assets and legal matters. The client's capacity to act is revoked by law.

Assistance, representative and advisory deputyships may be combined with each other.

In general, the progressive model of deputyship is consistent with the principle of proportionality. Case-analysis and measures taken by the authorities of adults respects this principle.

### **Turkey**

The guardian candidate (the relatives of the person, the neighbours or the ex officio guardianship authority) can request guardianship within the grounds that would require the person to be placed under guardianship.

A full guardianship model is applied for people with dementia. Apart from dementia, each cause of

guardianship is evaluated and decided within to its own circumstances.

There is moderation in general, for example, if the power of discernment has not completely disappeared (partial capacity), only the authority to carry out certain tasks and operations can be delegated. But where there is no power of discernment (full incapacity), authority is complete. When a plenipotentiary guardian wishes to act on behalf of the person with dementia, they must obtain permission from the guardianship authority.

### Ukraine

If an agent refuses to act on the agreement with the granter (a person with dementia who was found lacking legal capacity) or if the misuse by the agent is discovered, the care and protection services, or court at the initiative of care and protection services can appoint another agent or guardian.

Upon the decision of these bodies, a person with dementia who is found lacking legal capacity can be placed into a government facility for people who are sick and/or lacking legal capacity. There is an option of a full guardianship in Ukraine when all the decisions for the person with dementia are made by the guardian. Also, if the person was found to have a limited legal capacity, the person retains some rights, depending on their level of capacity (as specified by the court), while other decisions are made by a third party.

The principle of proportionality (granting powers only insofar as necessary to protect the interests of the person) is observed when a person determined to have limited legal capacity. The extent of legal capacity is decided in court ruling, which is usually started on the basis of the statement by a third party (usually a relative) or an application by protection and care services.

### United Kingdom – Scotland

The Adults with Incapacity (Scotland) Act 2000 provides a framework for safeguarding the welfare and managing the finances of adults (people aged 16 or over) who lack capacity due to mental illness, learning disability, dementia or a related condition, or an inability to communicate.

The key areas of Legislation are underpinned by principles which must be given effect by anyone acting under the legislation.

For the Adults with Incapacity (Scotland) Act 2000, these are:

- Benefit the adult
- Be the least-restrictive option in order to obtain that benefit
- Take account of the past and present wishes of the person
- Consultation with relevant others
- Encourage the person to use existing skills and develop new skills

For the Mental Health (Care and Treatment) (Scotland) Act 2003, as a general rule, anyone who takes any action under the Act has to take account of the principles. There are 10 principles:

- Non-discrimination
- Equality
- Respect for diversity
- Reciprocity - Where society imposes an obligation on an individual to comply with a programme of treatment of care, it should impose a parallel obligation on the health and social care authorities to provide safe and appropriate services
- Informal care - Wherever possible, care, treatment and support should be provided to people with mental disorder without the use of compulsory powers.
- Participation – Individuals should be fully involved, so far as they are able to be, in all aspects of their assessment, care, treatment and support. Their past and present wishes should be taken into account.
- Respect for carers
- Least restrictive alternative
- Benefit
- Child welfare.

The overarching principle of the Adults Support and Protection (Scotland) Act 2007 is that any intervention in an individual's affairs should provide benefit to the individual and should be the least restrictive option of those that are available which will meet the purpose of the intervention.

This is supported by a set of guiding principles which, together with the overarching principle, must be taken account of when performing functions under the Act. These are:

- The wishes and feelings of the adult at risk (past and present).
- The views of other significant individuals, such as

the adult's nearest relative; their primary carer, guardian, or attorney; or any other person with an interest in the adult's well-being or property.

- The importance of the adult taking an active part in the performance of the function under the Act.
- Providing the adult with the relevant information and support to enable them to participate as fully as possible.
- The importance of ensuring that the adult is not treated less favourably than another adult in a comparable situation.
- The adult's abilities, background and characteristics (including their age, sex, sexual orientation, religious persuasion, racial origin, ethnic group and cultural and linguistic heritage).

## 11. Experiences of people with dementia and carers

As with previous years, Alzheimer Europe wanted to ensure that the voices of people with dementia and carers were heard in our Yearbook. Whilst the Yearbook provides the policy and legislative context of legal capacity and decision-making, it is not in itself able to convey the experience and impact of them and what this means to people living with the condition. As such, we asked members of the European Working Group of People with Dementia (EWGPWD) and the European Dementia Carers Working Group (EDCWG) to contribute their experiences, to underscore the importance of policy, legislation, services and supports responding to the needs of people with lived experience.

In the first part of this section, we have provided a brief overview of some of the issues which emerged during consultations (two meetings with each group in 2023). In the second part of this section, we hear from a selection of carers and people with dementia who contributed written testimonies for inclusion in the yearbook.

### 11.1. Key issues raised by people with dementia and carers

During meetings with the groups Alzheimer Europe was able to identify a number of key issues which were important for both carers and people living with dementia, in relation to proxy powers, legal capacity and decision-making.

Whilst members of both groups were aware of the situation in their country and had arrangements in place for their own circumstances, it was felt that awareness amongst the broader public was not as high, as there were no campaigns to raise awareness about what powers of representation were or why people should have them. It was felt that improving awareness and understanding amongst the public should be a priority for governments.

The motivating factor for creating such powers varied considerably, with some having created powers before receiving a diagnosis of dementia because of other experiences (e.g. with other family members). Others did so following their diagnosis, however, there were significant variations on where the advice to do so came from; in some cases, the professionals involved in the diagnosis advised the person, whilst others received this advice from Alzheimer's associations.

Another recurring theme during discussions with both groups was the importance of involving a number of family members during discussions about their wishes and in the development of proxy powers, even where the family members may not be the decision-maker(s). The timing of when such discussions should be held are entirely unique to the person and their unique circumstances. Doing so directly after receiving a diagnosis may not be the right time for many, as people need time to come to terms with the diagnosis. It was also felt that conversations about wishes and decisions should be ongoing, especially for advanced directives, as a person's wishes may change over time.

Both groups were in favour of tiered approaches in decision-making being adopted, especially such as those found in the reformed Irish legislation, as it was felt that this gave people with dementia the greatest autonomy for as long as possible, whilst still providing for measures where the person needed support, particularly in the later stage of the condition. However, especially as this embedding of supported decision-making is new, there were questions about how this would work in practice, especially in instances of disagreement between supporters and the person themselves.

For carers this latter point was a concern, as they noted that balancing the wishes of the person and themselves (especially around care decisions), was often challenging and could be emotionally and mentally exhausting. They also noted that where circumstances change significantly and/or rapidly (e.g. a deterioration in the person's capacity or health),

decisions may need to be taken quickly, which policies or legislation don't necessarily accommodate.

Additionally, carers noted that there was additional complexity where a person was in a care home and the carer held proxy powers. The experiences of carers in this regard varied considerably. Some had a positive

relationship in which the care home understood the role of the power of attorney and involved them in decisions about the person, including relating to the provision of care. In other cases, carers were excluded from decisions relating to the care of the person, despite holding proxy powers.

## 11.2. Testimonials of people with dementia and carers

**Chiara Benelli, carer of Stephen McCleery (member of the EWGPWD)**



Our situation is quite complicated: Stephen is a UK citizen, but he lives in Italy; he pays taxes in Italy to a forensic fund and not to the Italian state; we are not married (and this is really a problem in Italy!). It's not simple for us to have support and make arrangements.

When Stephen started having memory problems, he gave me a general power of attorney, but I think this is valid only in Italy and not in the UK. A few months ago, I sent the Italian POA to an English lawyer to find out if it was also valid in the UK, but I never received a response...

As a lawyer, he has many lawyer friends who help us with the most important decisions, but in everyday life it is not so simple.

Unfortunately, Stephen is no longer able to make decisions. Even when he could do it, he didn't want to. Making decisions agitates him, even the simplest ones.

Having lived with him for more than 20 years, when a decision has to be made, I think about what he would have done. Sometimes I share decisions with his sister who lives in the UK. I think this is the right thing to do.

People with dementia need support in everything that affects them, at home and outside, in their private and social lives. The most important issue, in my opinion, concerns the rights and duties of people who are no longer able to work or make decisions. For example: How and when to start invalidity or incapacity pension practices. I add that all specialist support requested and received up to now (psychological, neurological and legal) has been done privately and for a fee.

**Sylva Dneboská**  
Member, EDCWG



After years of caring for my husband it came to the situation where the question of legal capacity became crucial. I had some experience from the past when I was the guardian to my brother (who was mentally

disabled from his very early childhood after cerebral palsy), so I knew how complicated, long lasting and time consuming it was to arrange Power of Attorney with Guardianship. Therefore, I wanted to learn if there could be other possible solutions.

I was quite lucky to be at that moment in contact with the organisation “AT HOME”, which was giving free of charge support to carers in various fields. They contacted me with their lawyer who recommended us to arrange General Power of Attorney (GPOA) signed by my husband and notary-certified. She explained me how the GPOA works, its advantages (quick and easy) and pointed out also its disadvantages (not valid in all cases e.g. with banks, possible misuse). As I had the full trust of my husband and of our children, we decided for the GPOA in this form.

I must say it worked, sometimes with some obstacles (when it was necessary to “bring” my husband – at that time already in wheelchair – to the bank) but it was manageable.

**Sonata Mačiulskytė**  
Chaiperson, EDCWG



I strongly support the idea that adults should have the authority to make decisions for themselves in all situations. However, the implementation of supported decision-making requires certain legal and institutional prerequisites, resource allocation, workforce training, and public awareness campaigns. Simply eliminating substitute decision-making will not be enough to enforce the provisions of the UN Convention on the Rights of Persons with Disabilities; in fact, it will worsen the violation of their legal and civil rights.

In addition to institutional and structural arrangements, we should fully empower the use of advance directives and power of attorney. However, many European countries still have limited legal frameworks for the first ones, which are further hindered by underdeveloped practices and lack of public awareness. The same situation applies to power of attorney. Various European societies have limited knowledge about this opportunity, including its conditions and limitations. It remains largely unknown until it is no longer legally viable.

As a family carer for ten years, I can attest that carers gradually become more involved in decision-making for our loved ones, whether or not we have formal authorization to do so. However, most of us are not adequately prepared for this role and require training. Furthermore, the more involved we become in

decision-making, the more it becomes necessary to be monitored and counselled. I also believe that we still have a long way to go in fully realizing the concept of supported decision-making. Some of us have a longer journey ahead, while others have a shorter one, but it is crucial to move in this direction now.

**Margaret McCallion**  
Vice-Chairperson, EWGPWD



As a family we had previously spoken of Power of Attorney, due to friends or relatives who experienced great angst as they had no say in the care their loved one may require or prefer.

It was actually when I was diagnosed that my Neurology Consultant suggested that my family got POA for me, which gave us all the 'nudge' we needed to contact the lawyer to arrange this. We explained that we had previously spoken about this and, due to one thing and another, it was not arranged (at that time).

Our lawyer came to our home, so everything was rectified in an ideal time frame with no stress experienced – just relief that it was actioned.

As a family, we all have a POA as well as our will for as and when they are required.

**Barry Northedge**  
Member, EDCWG



How would you feel if someone told you where you were going to live or what you were going to wear, when you were going to have a bath or when you were going to bed? How would you react if the most basic human right of choice were to be taken away from you, if all decisions relating to your life were being made by someone else?

This is what happens to so many people in the latter stages of dementia. When the disease has progressed to the point where the person is no longer capable of making reasoned and safe choices for the everyday parts of their lives. Decisions are taken by carers, care home staff, doctors and nurses, quite probably in, what they feel, are the best interests of the person they are caring for but quite possibly contrary to the wishes



of the individual. How do we avoid this? How do we ensure that a person's human rights are preserved and their preferences and choices are honoured?

My mother-in-law, Maud, had been living with dementia for a number of years, but my father-in-law, Tom, had been in fine health; an active, bright man who liked to be in charge. All that changed the night Tom suffered a stroke, causing him to fall downstairs, banging his head against the wall at the stair bottom. Whilst Tom recovered from the stroke, the incident triggered vascular dementia. Literally overnight Tom began to struggle to understand what was happening to him and around him, his character changed and he was no longer able to cope and look after Maud on his own.

This is where the Power of Attorney became vital to maintaining the lives of Maud and Tom. We were able to explain what a Power of Attorney was, what responsibilities would be granted to the chosen attorneys and why this was needed to safeguard their futures. Fortunately, we were able to have these discussions whilst both Maud and Tom were still capable of understanding everything being discussed

and agree. Power of Attorney documents for financial and wellbeing were drawn up and signed by Maud and Tom granting the Power of Attorney to Margaret, my wife, and her brother Thomas.

What followed was a gradual transition from shared decisions made by the family, fully including Maud and Tom, through to the point where all finances needed to be managed and, eventually, decisions on wellbeing also needed to be made on their behalf, but the transition enabled lots of informal chats so that everyone was absolutely clear about the wishes of both Maud and Tom and ensured that those wishes were and, in Maud's case, are still being honoured. Tom sadly passed away on 4 December 2022 but Maud still lives a happy life with support in her own home, still doing the things that she loves, knowing that everything is being taken care of in accordance with her wishes and choices.

Finally, a personal consequence has been that both Margaret and myself have legally given the Power of Attorney to our sons to be enacted should, for any reason, we become incapacitated. Our future wishes are secure!

**Helen Rochford-Brennan**  
**Former Chairperson – EWGPWD and Vice-Chairperson – Irish Dementia Working Group**



N.B. This contribution was originally published in the Dementia in Europe magazine, edition 43, however, given its relevance for this topic, has been republished with permission from Helen.

My journey into advocating for legal capacity reform through Ireland's Decision-Making Support Service has been a transformational experience that has empowered not only myself but countless others living with disabilities, particularly those with Alzheimer's. It all began for me with a concern of human rights and a law rooted in history. Today I am elated to see the positive changes in law that reflect the rights and dignity of all individuals, regardless of their cognitive state.

My involvement in the Assisted Decision-Making (Capacity) Act research, facilitated by the University of Galway Centre for Law and Policy, marked the genesis of my advocacy work. As part of my research, we

looked into the historical context of the Regulation of the Lunacy Act. The archaic nature of such legislation was disturbing; I recognised that people like me, living with Alzheimer's, deserved modern, empathetic and empowering legal structures.

Contributing to the book "Global Perspectives on Legal Capacity Reform: Our Voices, Our Stories" alongside my fellow researchers became a milestone. We collectively shed light on the real-world impact of outdated laws on individuals' lives and shared our unique experiences, challenges and aspirations. Our stories painted a vivid picture of the dire necessity for reform. Participation in this research not only gave me a platform to express my concerns but also helped galvanize a movement for change. At every opportunity we lobbied government officials to finally enact the Assisted Decision Making (Capacity) Act, this was a necessary precursor to Ireland's ratifying the UNCRPD.

Becoming a Champion of the DSS was a natural progression. I was delighted to be asked by the Mental Health Commission to be involved and share the voice of a person with dementia. With first-hand experience of the challenges faced by individuals living with dementia, I felt an inherent responsibility

to amplify their voices and champion their rights. This role allowed me to bridge the gap between academic research, personal narratives, and practical change. Advocacy ceased to be a mere endeavour; it transformed into a mission with tangible outcomes.

Today, as I reflect on the path I've walked, I am filled with a profound sense of accomplishment. The changes in law brought about by our collective efforts signify a paradigm shift in how society views individuals with cognitive impairments. Ireland's DSS is no longer a mere concept; it's a reality that validates the autonomy, dignity, and humanity of people like me. The recognition of our agency, our personhood, and our right to make decisions about our lives is a testament to the power of advocacy and the resilience of the human spirit.

My journey from concerns about antiquated laws to becoming an instrumental part of legal capacity reform exemplifies the potential of individual advocacy to spark systemic change. Every hour dedicated to this cause, every story shared and every lesson taught has culminated in a brighter future for all those affected by cognitive impairments. The DSS stands as a beacon of progress and I am proud to have played a role in shaping its evolution.

**Kevin Quaid**  
**Vice-Chairperson – EWGPWD and Chairperson – Irish Dementia Working Group**



There comes a time in most people's lives when they have to make arrangements for when a person who is seriously ill or when something bad happens and the person may need constant care. These decisions are more often than not taken by the family and sometimes without the person who is ill, which can sometimes lead to disagreements within the family.

When I was diagnosed with Lewy Body Dementia, it took about six months before it really sunk in for me, and both my wife and I began to talk about the future and what could happen, and what we should do and put in place for the future. I have a family of three children and three stepchildren and we decided to discuss my future with them. We did it on one to one basis at first but the kids are so close that they discussed it among themselves as well and a lot of

the conversations were uncomfortable; there were a lot of tears.

Remember, they were talking about when their Dad was no longer able to do things for himself and may need to live in a care home facility and may no longer be able to make decisions for himself.

We discussed everything from power of attorney, my funeral, and what care home I would like to go into, we spoke about whether or not I wanted to be resuscitated if I was very ill in the hospital.

These discussions took place over a number of weeks and as some of my children are in Australia. I was able to visit and have those discussions face to face with everyone. The general consensus was to support whatever I wanted, so as soon as we had all of the discussions out of the way, we went to our solicitor and put in place the people who are involved in the Power of Attorney. For me it was a learning experience

and I now know what exactly is involved in it.

For us as a family, it was one of the hardest things that we have ever had to do and over time I have asked each and every one of them if they were happy that they did it with me. The answer was the same from everyone, they did not like it when we were talking about it but when they had time to sit and think about it, they realised that if and when the day comes, they know exactly what dad wants, Helena knows exactly what her husband wants and for me it took away the worry of how would they cope if they had to make decisions for me and not sure if it's what I wanted or not. That worry is no longer there, and my advice to everyone is to do your forward planning as soon as you can. You don't have to have a disease to do it, because if something happens suddenly to you as it does to so many people every day of the week then your wishes are known and carried out. For us as a family, it brought us closer and it gave them a better understanding of where this disease may take me.

**Trevor Solomon**  
Vice-Chairperson, EDCWG



Even before my wife was diagnosed with young onset Alzheimer's disease, we already had Lasting Powers of Attorney (LPAs) and wills in place on the basis that one never knows quite what will happen in life. The process for the LPA was relatively straightforward, albeit rather expensive in the UK and we also invested in the expertise of a wills specialist to ensure we had made adequate and proper provision for our children.

Notwithstanding these important legal documents which were all about futures, I wanted my wife, post-diagnosis, to maintain her independence, her dignity and her feeling of self-worth by involving her in as much decision making as her cognitive ability would allow. We were after all a husband and wife team, so fostering her inclusion was really important to me.

In the immediate post diagnosis period, my wife's autonomy remained quite intact, but as the disease inexorably progressed, so her ability to make decisions also diminished. Choosing became difficult for her whether for example what clothes to wear or what food to eat in a restaurant, so restricting choice empowered her to still exercise control, boosting her

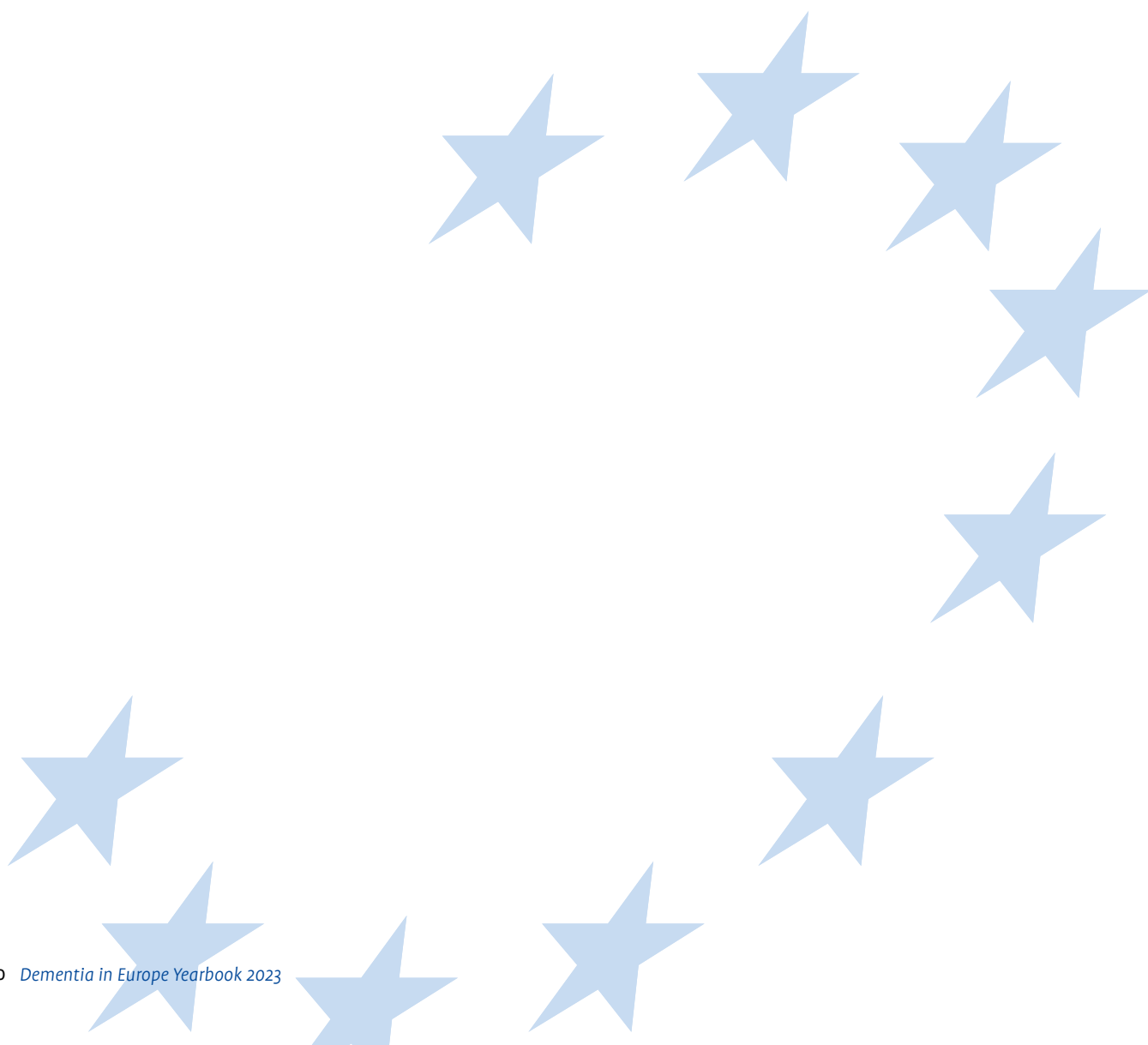
self-esteem and frankly alleviating some of my stress as her carer.

I learnt too that the increasing importance of clear, simple verbal communication and body language, being patient (not always easy) and allowing sufficient time for my wife to respond all supported her to process and make many of her own decisions. However, we inevitably reached the point where she couldn't make decisions at all because her brain was no longer able to process even the simplest of requests or instructions.

One aspect of decision making in which I chose not to involve my wife was in regard to her long-term care. This was not a deliberate decision on my part to avoid

the conversation but I felt it would greatly distress her and I also knew other carers who had made promises to their loved ones to always look after them at home and then could not shake off feelings of guilt when this became impossible, with the only option eventually being residential care. I truly believe there was this unspoken understanding and trust between me and my wife that I would always make the best decision for her about her long-term care.

Supporting people living with dementia to make their own decisions is essential for their well-being and overall quality of life but it cannot be based on a formulaic "one size fits all" approach; rather, it has to be tailored communication which recognises and embraces the person as an individual.



## 12. Good practice resources and further information

In this section, we have collated links and further information in relation to legal capacity and supported decision-making. Naturally, the level of information varies by country and by the source of the information (i.e. whether provided by our members, government or other organisations). This section is not intended to be exhaustive, however it provides good examples of how this information can be communicated.

### 12.1. Alzheimer's associations

#### Belgium

Through its slogan A.I.D.E (Accueillir, Informer, Défendre et Écouter - Welcome, Inform, Defend and Listen), the Alzheimer's League aims to provide a source of information and support for people affected by Alzheimer's disease.

It provides information sheets on the various forms of legal aid which are available to persons with dementia and covers issues such as civil liability, inheritance or donation, and the status of caregiver: <http://tinyurl.com/4wx38d39>

Alzheimer's League also provides training courses for professionals, families and local authorities in relation to legal and financial aid for dementia in general, and Alzheimer's disease in particular: <http://tinyurl.com/4x8d8k7w>

In addition, the association provides the necessary documentation on legal issues. A legislation section groups together documentation in paper format (monographs, periodicals, periodical articles, reports, brochures, etc.) and in electronic format. Here is the link to the documentation centre catalogue: <http://tinyurl.com/ydznz4ah>

The Flemish Alzheimer's Association makes legal topics available for a broad audience through printed publications, online resources on their website and tailored training sessions: <http://tinyurl.com/bden2hrd>

The Flemish association is also an official partner organisation of the Belgian Disability Forum, where they are active on the topic of legal rights for people with dementia as part of the broader disability policy

at a national and European level: <http://tinyurl.com/bdfcxfut>, as well as being a member of the Flemish Patient Platform (Vlaams Patiëntenplatform) where the legal pillar of the patient rights is one of the key areas of work: <http://tinyurl.com/mbk3dckp>

Through our 'Flemish working group of people with dementia' and the new 'Flemish working group for caregivers of people with dementia' we advocate for more transparency and supported-decision-making concerning legal rights following the rights-based approach set out by the framework of the UNCRPD. Currently they are working with both groups on a publication that will contain the future policy challenges in their area as a lobby document for the 2024 elections. There will be a dedicated chapter on the legal rights for people with dementia and their caregivers as one of the future actions highlighted by the working groups. Entitled "Samen bouwen aan een slagkrachtig dementiebeleid: Memorandum 2024 " (Building together for a decisive dementia policy: Memorandum 2024), it is available at: <http://tinyurl.com/59d35a24>

#### Czech Republic

On its website, the Czech Alzheimer Society publishes information and resources in text, short videos and print brochures, with a dedicated section on legal aspects pertaining to dementia: <http://tinyurl.com/jvt59cbn>

In addition, the association provides a course for professionals entitled "Introduction to the legal aspects of social service provision for social workers and managers", which is specifically focused on legal aspects related to dementia: <http://tinyurl.com/3uy5t896>

The association also provides courses for caregivers, with one of the topics covered being legal issues.

In addition, the association provides personal consultancy for people with dementia and carers, as well as draft forms for people who need to go to court.

### Denmark

The Danish Alzheimer Association offers telephone legal advice from lawyers and social workers. In addition, the association gives online lectures relating to legal issues including supported and shared decision-making targeted towards newly diagnosed people with dementia and their relatives.

Daily telephone counselling is provided by dementia staff who assist with anonymous dementia counselling relating to legal issues, including supported and shared decision-making and cross-border protections.

### France

France Alzheimer has information on legal measures relating to dementia available on its website: <http://tinyurl.com/sz4mmbxj>, as well as a dedicated flyer (which is not available on our website) that our network of local branches distributes.

In addition, the organisation offers training for professionals on various issues related to dementia. For the subject of legal capacity, the following training programmes address this issue including:

- Respond to a refusal of care
- Support young people living with dementia
- Caring for a person with dementia at a late stage of the disease.

More information on these training courses can be found at: <http://tinyurl.com/2p9e2786>

This is the law and it remains very complicated, mainly for people living with dementia in nursing homes, as it can be difficult for professionals to accompany people to vote on the due date. We see that there is also a lack of information on this specific evolution and that the information needs to circulate more. In 2022, before the presidential election, France Alzheimer participated in the approach of the Cercle

“Vulnerabilities and Society”: “My voice counts”: <http://tinyurl.com/3fwvduiez>

Presentation:

“As part of the promulgation of the 2018-2022 programming law and the reform for justice (March 25, 2019), people with disabilities or frailties are granted recognition of their full and complete citizenship. Article L5 of the electoral code, which made the right to vote of persons under guardianship subject to a decision by the judge, is therefore repealed (300,000 adults are currently under guardianship in France).

The Cercle project is therefore part of this dynamic, and the objective is to promote the broadening of the democratic voice of people with mental, psychological, and cognitive disabilities. It is urgent to raise the awareness of as many people as possible - facilitators in establishments, tutors and people concerned - about the possibility of reclaiming a civic right as well as the feeling of belonging to a community, particularly in the context of the next electoral deadline.”

### Finland

The Finnish Alzheimer’s Association has carried out development projects that have researched and gathered some information on supported decision-making. However, the information from these projects is used more in everyday/private context and in relation to health and social services regarding how to find information and make decisions related use of services.

### Germany

The German Alzheimer’s Association has two key resources relating to legal capacity and supported decision-making.

The first is a guidebook aimed at people with dementia, their relatives, professionals and volunteers. It provides detailed information on legal and financial matters relating to dementia: <http://tinyurl.com/2se9h8v5>

The second is a collection of information sheets spanning different topics including voting rights, guardianship legislation, long-term care insurance, liability issues etc.: <http://tinyurl.com/2e9x2yd5>

The third is information on the right to vote: <http://tinyurl.com/89xu8t9y>

### Ireland

The Alzheimer Society of Ireland has information related to the Assisted Decision-Making Act 2015 on its website at: <http://tinyurl.com/v2pjzy74>. In addition, it is providing information about the Act to its staff and members of the public, including the types of support arrangements the Act will make available and how the Codes of Practice will affect how health care staff practice.

### Malta

The Malta Dementia Society organises two talks annually that specifically focus on legal issues pertaining to dementia. These talks are open to the public and are delivered by a legal professional.

The general public can also contact the Society with queries of a legal nature which will be passed on to a professionally trained legal professional for reply.

### Poland

Alzheimer Polska member organisations offer advice on legal matters to persons visiting or calling, mostly carers. Whilst it does not publish its own resources on those issues, it refers to publications which have been published by the Office of the Human Rights Commissioner, which can be accessed on its website: <http://tinyurl.com/4tscx9zf>

### Portugal

Alzheimer Portugal has a number of online resources covering different aspects of decision making and legal capacity of people with dementia, including:

- The rights of people with dementia  
<http://tinyurl.com/233p8w96>
- Living wills and healthcare powers of attorney  
<http://tinyurl.com/3a4dbh6b>
- The Accompanied Adult Regime  
<http://tinyurl.com/9k75z6at>

### Spain

The Spanish Confederation of Alzheimer and other Dementias has published a legal study on its website, which offers an overview of the guarantee of the rights

of people affected by Alzheimer and other dementias. However, the study is dated and the association is working on updating the study to reflect new legislation: <http://tinyurl.com/z4v8atzs>

In addition, the association has published an online webinar on the legal capacity of people with dementia, reflecting the new legislation: <http://tinyurl.com/33vypj8p>

The Spanish Alzheimer's Federation only provides basic recommendations to individuals, instead referring persons concerned to the "Illustrious Bar Association of Madrid", which provides free legal assistance in this area.

### Sweden

The Dementia Association holds information meetings for the general public, as well as providing legal support to its members. Legal information is available on the Dementia Association's website:

- About dementia  
<http://tinyurl.com/5n6hesrf>
- Living with dementia  
<http://tinyurl.com/a5xu4mty>
- Relatives of a person with dementia  
<http://tinyurl.com/msbpfh43>
- Younger persons with dementia  
<http://tinyurl.com/4x77kt7r>

### Switzerland

Alzheimer Switzerland offers regular training modules with regard to the Swiss system of advanced care planning and adult protection. In addition, the association offers free individual counselling on a national and canton level which addresses all the issues relating to decision-making and legal capacity on an individual level.

In addition, the organisation has a number of publications which address this subject, including:

- Brochures  
<http://tinyurl.com/2pnx85ae>
- Information sheets  
<http://tinyurl.com/3w4aexhy>

**Turkey**

The Turkish Alzheimer Association organises regular seminars by a Forensic Medicine Specialist, where the caregivers participate and learn about their social and legal rights and responsibilities.

In addition, the association gives training to neurologists and researchers and organizes workshops regarding the legal rights of people with dementia. From July 2023, five cities in the far-east of Turkey will be visited within 12 months by the experts of the association to give two-day trainings to local people on the subject of care for people with dementia, as well as the social and legal rights of the person with dementia and the caregiver.

**Ukraine**

Nezabutni organisation has commenced work with a lawyer who provides consultations for people with dementia and their caregivers. The organisation is in the process of working on a guidebook for legal questions for people living with dementia and their caregivers.

## 12.2. Government and other associations

**Czech Republic**

Organisations like Cesta domů (primarily for patients with terminal illness) publish brochures on previously expressed wishes and provide social and legal counselling. In addition, they provide education for both professionals (including healthcare professionals) and the general public: <http://tinyurl.com/56e9uafz>

**Denmark**

Some municipalities in Denmark offer teaching on rights and legal advice targeted at PwD and their relatives. Likewise, some municipalities offer lectures on legal topics and often in collaboration with the Danish Alzheimer's local associations. In Denmark all the municipalities have employed Dementia coordinators to provide advice related to legal and legal issues.

**France**

The resources of Fondation Médéric Alzheimer provide information on legal protections for people who can no longer provide for their interests, as specified in line Article 425 of the Civil Code. The resources explain the three different measures (safeguarding justice, curatorship and guardianship), with a specific focus on what this means for the individual and what the process for each measure is: <http://tinyurl.com/u46wjxxu>

**Germany**

A brochure from the Ministry of Justice on the main features of guardianship law and information on health care proxies and the associated forms can be found here: <http://tinyurl.com/px6f4v7h>

**Ireland**

The Decision Support Service (DSS) was set up within the Mental Health Commission and oversees the implementation of the new Assisted Decision Making (Capacity) Act. Information on the Act is available on the DSS website: <http://tinyurl.com/ckv9npen>

The DSS contains a “story database” in which examples of how the Codes of Practice may be used to guide practice in real life situations. At the time of writing, the stories are all vignettes, however, as the Codes come into use, the DSS intends to update the database to include anonymised cases: <http://tinyurl.com/yzxrsn68>

The DSS also launched a series of videos to raise awareness using “DSS Champions” to share their stories of decision-making and how the new laws and services support them and helps maintain their autonomy: <http://tinyurl.com/y6zapzh3>

The Health Service Executive (HSE) holds webinars on practical considerations for commencement of the Assisted Decision-Making Capacity Act 2015, including information about the DSS (e.g. how to interact with the DSS, Codes of Practice, DSS Register), Wardship transition, Decision-Making Representative applications and other key issues: <http://tinyurl.com/2nn2fbds>



On HSEI (the Irish Health Service’s national online learning and development portal) offers dedicated training for all healthcare staff, which consists of three modules, including Guiding Principles of the Act; Working with decision supporters appointed under the 2015 Act; and Advanced Healthcare Directives: <http://tinyurl.com/4ruz4ea>

### Netherlands/other

The Academy of International Comparative Law met in Asuncion (Paraguay) in 2022 and discussed several country reports on protection of vulnerable adults. More extensive and current country reports about this topic can be found on the site of FL-EUR (Family Law in Europe): <http://tinyurl.com/4zd4dxvk>

### Poland

The Office of Human Rights Commissioner publishes (on its website and in print) information and advice on legal matters concerning older persons, including persons living with dementia, as well as information about campaigns e.g. on the rights of persons with Alzheimer’s disease.

Each year, Alzheimer Polska is invited to co-organize a conference on dementia. The event is recorded and available, together with other publications on dementia at: <http://tinyurl.com/47n8ruvj>

### Sweden

There are a number of organisations that provide information on this subject, including some which work on behalf of the government:

- National Competence Centre for Relatives  
<http://tinyurl.com/6etnbz37>
- Swedish Dementia Centre  
<http://tinyurl.com/4f5ese2k>
- National Board of Health and Welfare  
<http://tinyurl.com/3dcpad3>
- The Board of Chief Guardians  
<http://tinyurl.com/59d92nna>
- Swedish Agency for Participation  
<http://tinyurl.com/yenr4fvm>

The Swiss authorities on the federal, cantonal and communal level publish information on legal issues, advance care planning and adult protection online. However, we find that personal counselling and training offers should and could be increased, as many people lack the required digital and literacy skills to make use of this information.

### Ukraine

The Government, through the Parliamentary Commissioner for Human Rights, provides information about aid (including legal aid) for people with disabilities and senior citizens. This aid is provided also to people currently abroad or in captivity (as much as possible): <http://tinyurl.com/2vhkwau>

State institutions (for example, the Centre for the Organisation of Psychiatric Aid in the State Institute of Psychiatry, Forensic Psychiatric Examination and Drugs Monitoring of the Ministry of Health of Ukraine”) collaborate with non-governmental organisations (for example, NGO “Institute of Social Studies in Kharkiv”, NGO “Laboratory of psychiatric health”, NGO “Laboratory for human rights”) on the questions of the rights of people with disabilities who are staying at the inpatient facilities during wartime: <http://tinyurl.com/2p9uh2ue>

## 13. Conclusions and recommendations

The first part of this section will provide some overarching observations regarding each of the previous sections, identifying common themes and trends emerging between countries, as well as observations about the extent to which international and European treaties are being adhered.

In the second section, recommendations have been developed for actions which can be taken at a European and national level to facilitate the move towards systems of supported decision-making, as well as to ensure that the legal rights of persons with dementia, under European and international rights conventions, are upheld.

### 13.1. Observations and conclusions

#### **National policies and strategies (including dementia)**

It was noted that, of the countries which do have national dementia strategies in place, only a few of these reference issues relating to legal capacity or have dedicated workstrands on the subject. Of those that do, the focus is mostly on raising awareness of the relevant laws and support, as well as the importance of future planning for decision-making. However, in some instances, the strategies referred to completed or ongoing legal reform in the field of legal capacity. Whilst understanding that matters relating to legal capacity cover a broad range of topics across a number of areas and given the implications for people living within dementia and their carers, it was surprising not to see more dedicated measures in dementia strategies.

Where dementia strategies did not exist or legal capacity was not addressed, countries provided examples of other policy areas in which matters pertaining to legal capacity, including plans and policy related to disability, ageing and end of life. Additionally, reference was made to dedicated work on bioethics and medical ethics, which addressed the issue of capacity and decision making. Additionally, dedicated work on models of service delivery and accessibility of supports related to decision-making were a recurring theme within other strands of work identified by members. Finally, a number highlighted resources created by themselves or other civil society organisations which addressed decision-making.

#### **Legal and decision-making capacity – Contractual and testamentary capacity**

The key theme emerging from the sections related to contractual and testamentary capacity was often subject to the person having decision-making capacity, which for the vast majority of countries is the default legal position. Whilst dementia did not *per se* render a person unable to enter a contract, where the person was deemed not to have decision-making capacity, proxies were generally permitted to make these decisions on behalf of the person, with the individual concerned losing legal capacity in this regard. In a few instances, a tiered approach to proxy measures meant that there was a role for a designated person to support the person to make a decision or enter a contract, however, this was only in place in a minority of countries. It was noted that, in most countries, where contracts were entered into where the person was found to lack decision-making capacity or where the contract was abusive, it could be annulled or voided, usually through the courts.

The approach of testamentary capacity was broadly similar, with decision-making capacity being an underlying requirement for making a will with the notary, solicitor or other relevant organisation determining whether the person had testamentary capacity (sometimes with the input of a medical professional). As such, in most countries, persons subject to proxy measures, including full or partial guardianship measures, were unable to make a will. Whilst dementia did not immediately prevent a person from making a will in the majority of countries, it

was noted that where there were questions about the person's capacity at the time of the will being created, this could leave the will open to challenge in court, with wills made when the person did not have decision-making capacity being annulled or declared void. As the presumption of decision-making capacity exists within most countries, it is up to the person contesting a will or testament to demonstrate the contrary.

Notably, the key distinction from contractual capacity was that proxies could not exercise testamentary capacity on behalf of the person and clearly express their wishes, as well as their understanding of the implications. However, in countries with tiered systems of substitute or supported decision-making, the person could be supported to exercise testamentary capacity, subject to certain conditions.

However, for both contractual and testamentary capacity, the underlying approach of legislation is focused on the decision-making capacity of the individual, which ultimately determines whether the person is considered to have legal capacity. Whilst some tiered approaches and those with elements of substitute decision-making emphasise the involvement and support for the person to exercise their own wishes, the use of decision-making capacity as the *de facto* means of determining legal capacity should be addressed.

### **Legal and decision-making capacity – Criminal and civic responsibility**

In the majority of countries, where it is determined that the person acted at a time where they did not have decision-making capacity and did not understand the consequences of their actions (for example as a result of illness), legislation usually determined that the person could not be held fully responsible for their actions. The effect of diminished responsibility varied, including the reduction or removal of punitive elements of a court's decision (e.g. fines or incarceration) and/or the exercise of alternative means, such as placement in secure facilities or treatment orders. Though it was noted that this was more commonly applied in instances of types of mental illness other than dementia.

By contrast, countries were more evenly split between those which held persons with incapacity as liable in cases of civic liability and those which did not. Notably, there were a number of countries that held guardians or supervisors liable instead or additionally liable in such cases.

### **Legal and decision-making capacity – Marriage and voting**

In almost all countries, capacity for marriage was dependent upon both individuals having decision-making capacity and not subject to proxy measures; though in a minority of countries, the presence of proxy measures (guardianship or others) did not automatically result in the person losing their legal capacity to get married. However, in such cases where the decision-making capacity of the person is in question, additional safeguards were usually put in place, including authorisation by a court (including during the guardianship process), determination by a notary or medical professional or consent of a guardian or supporter. However, the nature of marriage as a personal act means that proxies cannot give consent on behalf of the person. Where marriages have been conducted involving a person, who at the time, was deemed to lack decision-making capacity,, some countries specifically noted that these would be annulled.

In most countries, a person's right to vote remained, regardless of a diagnosis of dementia or a loss of either decision-making or legal capacity. However, there are a small number of countries where the loss of these capacities resulted in the loss of the right to vote (in some countries this is part of the guardianship decision and the court will determine voting rights). A number of countries also noted that where a person needed assistance to vote, this was permissible, subject to certain rules. However, whilst a person may be assisted to vote, it was highlighted by a number of countries that this could not be exercised by proxy decision-makers.

### **Consent to treatment and research**

Consent to treatment varies by country, however, the general underlying principles is that the will and preferences of the incapacitated person should be respected, with informed consent of the person

sought for treatment, with the most commonly cited exception being in cases of emergency where life-saving treatment is to be administered (where not covered by advanced directives etc.). Although not mentioned in all countries, there was some emphasis on the provision of information in clear and accessible formats which allowed a person to make decisions based on informed consent; however, only a few countries specifically referenced the importance of information adapted to the specific needs of the patient.

Where a person cannot express their wish regarding treatment decisions, or requires support to do so, countries had different approaches, including:

- In the majority of countries, a power of attorney or guardian may be consulted by medical professionals to make a treatment decision, however, this must be specified when the powers were officially created
- A minority of countries had provisions for some form of healthcare proxy or supporter (separate to another power of attorney or guardian), appointed when the person has decision-making capacity
- A minority of countries had provisions for advance directives (with varying degrees of legal weight), made when the person has decision-making capacity

Of note, a recurring theme across most countries was the need to ascertain and consider the will and preference of the person, even where the person was deemed to have lost decision-making capacity and/or where proxy powers were in place, with previous expressions of preference expected to help reach a decision as to what the person would want.

Laws relating to consent to research were broadly consistent with those of consent to treatment, insofar as most countries allowed proxies to consent on behalf of the person in instances where the person themselves did not have capacity. However, there were usually additional conditions and/or safeguards in place. For example, a number of countries highlighted the ethics committees which make determinations on research participation, especially where there are difficulties around consent or the involvement

of people lacking capacity (in this case, to decide on possible involvement in a specific research project). Further examples included the need for there to be direct benefit to the person taking part in the research, the lack of a suitable alternative research approach and minimal risk/harm to the individual.

### **Powers of representation/attorney**

Powers of representation were present in all countries, allowing individuals with decision-making capacity to designate another person or persons to make decisions on their behalf whilst they had decision-making capacity. This was most commonly done through a solicitor or legal notary, with some countries having an external body with whom the document needed to be registered. Countries also differed in whether the power of attorney came into effect immediately from the point of being made or was activated when the person was deemed to have lost capacity (sometimes by presentation of a medical certificate).

Proportionality was found within power of representation systems in a number of different ways, including through different types of powers of representation (e.g. healthcare, financial or welfare powers of attorney), which separated out different powers, although general powers of attorney were broader and usually covered multiple areas. However, as noted in other sections, powers of representation were usually specific and defined the actions which the proxy was permitted to undertake and limited the ability of the proxy to exercise decisions on behalf of the incapacitated person. Additionally, some countries noted that it was possible to have time-limited powers of attorney, usually to achieve a specific outcome (e.g. completing a specific transaction). One aspect which was notable in the majority of countries was the lack of oversight for the use and exercise of powers of attorney. Whilst a small number of systems required reporting to a centralised body (especially in relation to financial decisions taken on behalf of an individual or to activate or register powers of attorney), the majority of countries reported that there was no monitoring of the use of powers, with any abuses needing to be pursued through courts after the fact. This does not help people lacking decision-making capacity to make such decisions in the first place, and who may be unaware of the abuse, or unable to take the necessary measures to report and challenge it.

### Substitute/supported decision-making

Where individuals do not have decision-making capacity and have not made any powers of representation, countries have provision for guardianship, allowing for decisions to be made on behalf of the person. Most countries reported that this was based on models of substitute decision-making, in which the person loses legal capacity and cannot take certain decisions on their own behalf (as outlined in the previous sections). These are usually granted through court orders, which set out the powers which a guardian may exercise, as well as setting out what powers or legal capacity the person retains.

Although guardianship orders can be made which are general and broad in scope, there were a number of countries which accommodated full or partial models of guardianship (i.e. where the person's legal capacity is fully or partially restricted). In other countries, a tiered approach was in place, with different levels of support or substitution in place, depending on the decision-making capacity of the person. Such tiered approaches were more commonly found in countries which had reformed their legislation since the introduction of the UNCRPD. Across countries, it was a recurring theme that powers are granted only to the extent necessary (determined by the courts), with a default to the lowest level of intervention deemed necessary. However, overt reference to supported decision-making is not widespread within legislation, even where the legislation or policy context may be promoting this approach (e.g. ensuring that people are consulted or involved in decisions which affect them), is not widespread across European countries. As with powers of representation or attorney, there were few systems which actively monitored guardianships, with most noting that abuses of guardianship would be subject to criminal investigation through the courts after the fact.

### Concluding remarks

From the contributions of members, it is evident that there has been some progress in the promotion and upholding of legal capacity in recent years both at a national and European level since the publication of the previous yearbook in 2016. However, it is clear that a number of countries have not reformed their systems and that substitute decision-making continues to be prevalent throughout much of Europe. It is welcome that, in 2023, the European Commission developed

and published proposals for a Regulation and Council Recommendation in relation to the Hague Convention on the Protection of Vulnerable Adults 2000. These are undeniably important in facilitating a European-wide system that facilitates people with dementia and families, carers and supporters living in cross-border situations however, it is somewhat surprising that the language within these proposals does not reflect a more rights-based approach and does not acknowledge the need for such systems to be UNCRPD compliant (for example, by including reference to supported decision-making). In addition, the General Comment No.6 (on Article 5 of the UNCRPD) published in 2018 has been useful in more clearly defining the interpretation of the Article and thus the expectations placed upon State Parties, including in relation to legal capacity, decision making and discrimination.

However, General Comment No.1 and its view that substitute decision-making is discriminatory and should be abolished continues to be problematic, especially as it overlooks the progressive nature of a condition such as dementia and gives no consideration to the practical difficulties that arise where no mechanism exists to take decisions where an individual cannot make decisions for themselves. Even in countries which have tiered levels of guardianship and/or supported decision-making articulated in its legislation, all recognise the importance of guardianship as a measure of last resort where supported decision-making is no longer sufficient. As such, Alzheimer Europe continues to believe that its combined supported decision-making model, articulated in its 2020 Ethics Report, remains more appropriate and feasible. It is also essential to consider the contributions and experiences of the EWGPWD and EDCWG, which highlight the need to take into account the wishes of the individual, their families and carers. Indeed, through the discussions with these groups, few took issue with the concept of proxy decision-making itself, but more so with the information provided around processes, as well as support for individuals and family. Members of both groups spoke of the importance involving people in decisions as far as possible, even where a Power of Attorney or Guardianship was in place, with ongoing conversations and discussions between the individual, family members and carers seen as essential.

## 13.2. Recommendations

Taking all of these points into consideration, Alzheimer Europe has developed recommendations for both national and European policy makers, which have been informed and reflect the consultations held with members of both the EWGPWD and EDCWG.

### Recommendations at a European level

- Dedicate programmes of work within ESF+/ Cohesion Funds to support the development of resources and projects which implement systems of supported decision-making for persons with disabilities in keeping with our position stated in this document, and building on the previous ethics work, should we not then also be recommending something about substitute decision making (e.g. as described in our model)? If so, maybe earlier on or somewhere in the text, it would be good to briefly explain the different stages of this model. There were about 5 stages and the last one was on substitute decision making. It could be presented in an info box.
- Adopt and implement the proposed Commission Regulation on cross-border situations and the Council Decision on the Hague Convention
- Amend or repeal the 1976 Electoral Act, in line with the legislative proposal of the European Parliament (P9\_TA(2022)0129) passed on 3 May 2023
- Revise the Regulation on Jurisdiction, Applicable Law, Recognition and Enforcement of Measures and Cooperation in matters relating to the Protection of Adults to align to the model of same as previous point-making in Alzheimer Europe's 2020 Ethics Report.



### Recommendations at a national level

- Reform laws relating to substitute decision-making, moving towards a system which prioritises a combined supported decision-making model, aligning to Alzheimer Europe's 2020 Ethics Report. As part of this:
  - Ensure some level of monitoring or oversight for the exercise of powers, without creating unnecessary or excessive bureaucracy for the person exercising the powers.
  - Ensure powers are regularly reviewed on an ongoing basis, especially where a person has a progressive condition which will affect their capacity.
- Provide funding for the development of public-facing campaigns to raise awareness and understanding of powers of representation and encourage people to make these arrangements and/or advanced directives, advising people where to go and whom to approach to get more information on the process.
  - Such campaigns should be framed as positive and affirmative for self-determination, which helps people to ensure that they are supported to live as they would want, when these powers need to be used.
- Governments (national and local) should develop and distribute resources on supported decision-making in relation to raising awareness, as well as developing practical tools and signposting information for those undertaking the role of supporter.
  - This should involve service providers, civil society organisations and other related professionals, and should be made as widely available as possible in public places (e.g. community centres, libraries, health centres etc.) and online.
- Ensure that relevant professionals (e.g. care home managers, clinicians in hospitals etc.) have the relevant training and knowledge on how powers of attorney and guardianship operate.
- Ensure that other professionals know where to direct people to receive additional information on proxy decision making. This is especially important for professionals involved during and after the diagnosis of conditions such as dementia.
- Repeal or reform laws relating to civil and political rights, including those related to marriage and voting to ensure that individuals are not disqualified by incapacity.



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**Alzheimer Europe** • 14, rue Dicks • L-1417 Luxembourg  
Tel.: +352 29 79 70 • Fax: +352 29 79 72 • [info@alzheimer-europe.org](mailto:info@alzheimer-europe.org)  
[www.alzheimer-europe.org](http://www.alzheimer-europe.org)



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