



*Making dementia a priority:
changing perceptions, practice and policy.*

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

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1. Introduction

Discussions about legal capacity and decision making often focus on laws and regulations, which affect what people are or should be entitled to and on what is or is not allowed to happen. These issues affect the lives and wellbeing of people with dementia. Legislation and guidelines determine and provide guidance on how to protect and promote people's rights and, to some extent, how to behave ethically towards each other. Failure to respect laws is by definition illegal but usually also unethical. However, this does not mean that laws guarantee ethical behaviour, protect everyone's rights or ensure that everyone has the same opportunities. This is why it is important to reflect on ethical issues linked to the concept of legal capacity. This document provides a short overview of some of the key issues that are relevant to legal capacity and decision making. These issues were addressed more fully in a comprehensive report drafted by Alzheimer Europe's ethics working group in 2020¹. We hope that this report will provoke reflection and ultimately, through the actions and attitudes of those reading it, bring about positive changes in how people with dementia are considered and treated in situations in which decisions need to be made about things that are important to them.

2. About legal capacity and decision making

Rights and abilities

'Legal capacity' is the term used to refer to the *right* to make decisions for oneself, within the constraints of the law, which must then be recognised as being legal. This could include decisions like getting married, buying a house, moving into a care home or having a risky operation. It could also directly or indirectly apply to everyday matter such as keeping a cat or dog, going on holiday, smoking, deciding what to wear or what to have for dinner, or having certain hobbies and friends.

People don't always have (or are deemed to lack) the *ability* to make a decision. This may result in them being described as lacking decision-making capacity and is often linked to assumptions about self-determination, independence and autonomy, which tend to be highly valued in mainstream European cultural groups. Decision-making capacity (sometimes called mental capacity) should always be considered in relation to a particular decision, at a particular moment in time, but sometimes generalisations are made. In some legal systems, this can lead to a global loss of legal capacity (i.e. a disproportionate measure).

Individual autonomy, with its emphasis on rational thought, often overlooks the importance of other values such as family harmony, filial piety (respect for parents and elders) and the importance of the community. This has resulted in growing recognition of the value of relational autonomy and of involving significant others in decision making. This needs to be combined with measures to ensure that their involvement in decision making is desired, appropriate and not abusive.

Disability, discrimination and equity

People with dementia do not always benefit from the same rights and opportunities as other people to participate in society. This is partly based on the difficulties they experience as a result of various impairments but also because of practices, attitudes and the way things are organised. This makes it difficult for them to exercise their legal capacity, which may be restricted or withdrawn.

The provisions of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) reflect an awareness of this complex relationship between impairments and disabilities. They also apply to people with dementia. Article 12 of the CRPD states that everyone, irrespective of disability, has the right to be considered as a person before the law in all aspects of life, that their decisions must

¹ The full report can be downloaded at: <https://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice>

be legally recognised and that appropriate measures must be taken to provide them with access to the support they may need to exercise their legal capacity.

The CRPD promotes the principle of equity, based on solidarity, and recognises that it is sometimes justifiable to treat people differently, rather than merely giving everyone the exact same opportunities². This is reflected in the concept of ‘reasonable accommodation’, which is described as consisting of:

“necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others all human rights and fundamental freedoms” (CRPD 2006, §5.3).

Such modifications and adjustments can be enforced through rules, regulations and laws, inclusive environments, as well as through carefully planned and meaningful involvement of people with disabilities in society. However, it is also necessary to challenge discrimination (i.e. the unfair or prejudicial treatment of people and groups based on characteristics such as race, gender, age or sexual orientation).

There is a link between discrimination and stigma in that whilst discrimination may occur in the absence of stigma, it is a component of stigma. Another component of stigma is stereotyping. Common stereotypes include people with dementia having symptoms which are in fact typical of late-stage dementia, and people with dementia not being able to do anything for themselves, being totally dependent on other people and having no quality of life. This can lead to assumptions about their decision-making capacity and to decisions about the kind of support or adjustments that can or should be made. It can also lead to value judgements, which may in turn contribute towards restrictions of their legal capacity.

Decision-making support is an example of necessary and appropriate modification of existing practices, which can help ensure, as far as possible, that people with dementia can exercise their legal capacity. The duty to provide reasonable accommodation applies to a wide range of stakeholders, including health care providers and providers of goods and services amongst others. It is a means and also an obligation to put an end to any situation of discrimination based on disability.

Different approaches to determining legal capacity

Any loss of the right to make decisions can have a considerable impact on people’s lives and wellbeing. Being formally and publicly declared as having no or limited legal capacity may have a devastating psychological, emotional and practical impact. For some people, it is experienced as an affront to their dignity, affecting their personal relationships with other people and their standing in the community. It has been suggested that depriving a person of their legal capacity amounts to considering them as a non-person. Legal capacity is therefore a legal concept but it is not just a legal matter. Legal capacity and decision-making capacity are interrelated and have social and ethical implications.

The European Union Agency for Fundamental Rights distinguishes between formal and informal restrictions of legal capacity. Informal restrictions are not based on a legal or even administrative process but on assumptions, paternalistic attitudes, ignorance and institutional procedures. However, both formal and informal restrictions of legal capacity result in the loss of the right to make decisions that are recognised by law.

² This is not discrimination (insofar as this term is typically understood).

There are several different approaches to determining whether people have the ability to make decisions and on what grounds their right to make their own decisions can be restricted or taken away. The most common approaches include:

The status approach, which equates a medical condition or impairment with decision-making capacity and considers this sufficient grounds to revoke legal capacity, regardless of a person's actual capacities. It reflects the medical model of disability and makes assumptions based on stereotypes. An example of this approach would be the loss of legal capacity to vote, drive or make a will based solely on a diagnosis of dementia.

The outcome approach, which focuses on the reasonableness of decisions that are made. A decision that others consider unreasonable (such as a refusal of necessary treatment) may lead to a person's legal capacity being revoked. It suggests that there are 'right' and 'wrong' decisions. It denies people the right to individuality and to live their lives according to cultural, social, philosophical, political and religious beliefs and values which differ from those of the majority population. It limits people's right to make mistakes and take risks.

The functional approach, which makes legal capacity dependent on actual decision-making capacity. People need to show that they can make an informed decision on their own and can understand the nature and potential consequences of a particular decision.

The sliding scale approach, which is one version of the functional approach. It provides a system of legal protection whereby a person is permitted to make certain decisions, either alone or with support, whereas others have to be made by a legally appointed representative. Some decisions are considered as requiring higher levels of ability than others. The threshold for functional decision-making capacity is linked to the level of risk associated with a particular decision.

All of the above-mentioned approaches make it possible for a person to lose legal capacity and for decision-making power to be handed over to other people. This does not respect the call in the CRPD for an absolute ban on denying legal capacity and for all regimes of substitute decision making to be abolished and replaced by supported decision making. At the same time, Scholten and Gather (2018) describe several adverse consequences linked to abolishing substitute decision making for people with mental disabilities. Examples include overlooking cases where people are not able to make decisions that will result in what they feel is best for them, difficulty determining collective responsibility, the extra time, money and effort needed for effective support, ambiguity about when support should be provided if not based on a lack of decision-making capacity. It also challenges the whole concept of advance directives, which, by definition, come into force when people lack decision-making capacity and have been declared as no longer having legal capacity. Scott Kim describes the justification for substitute decision making as follows:

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

3. Supporting and empowering people with dementia

The combined supported decision-making model

In our view, it is not helpful or even ethical to focus solely on a concept (such as everyone having legal capacity, irrespective of their ability to make a decision) that does not work for all members of society. An effective and fair system is needed, which corresponds to everyone's needs and seeks to provide

all possible support needed to exercise legal capacity. We believe that such a system should also incorporate substitute decision making to the extent that this is necessary, proportionate and carried out in an ethical manner. We therefore promote the combined supported decision-making model developed by Scholten and Gather (see below). This incorporates substitute decision making, if deemed necessary. It is not discriminatory as any potential loss of legal capacity is not based on belonging to a particular group but rather on the assessment of a person's ability to make a specific decision about a specific issue at a specific moment in time, having been provided with all possible appropriate support. The model is comprised 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 this 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 would not be sufficient.
3. **Assessment of decision-making capacity:** An assessment of decision-making capacity is carried out. If the assessment shows that the person possesses the required abilities, they can make their own decisions and these decisions will carry legal effect.
4. **Supported decision-making:** If the assessment shows that the person's decision-making abilities are substantially impaired, supported decision making should be provided to enable them to make their own decisions (such decisions would then carry legal effect).
5. **Monitoring:** Supported decision-making should be monitored to ensure that it enhances the person's ability to make a decision and that undue influence is not exerted on them.
6. **Substitute decision-making:** 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 whose functional decision-making capacity is substantially impaired. Such decisions should correspond to the 'best interpretation of the person's will and preferences'.

The combined supported decision-making model is in agreement with the CRPD's general principles of equality and non-discrimination (Scholten, Gather and Vollmann (2021)). It respects and promotes the autonomy of people with dementia in three ways:

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

In addition, it protects people with dementia who are vulnerable due to impaired decision-making capacity against abuse and undue influence.

Promoting autonomy and avoiding paternalism

For people with dementia, there is always a risk of pervasive paternalism affecting the evaluation of their decision-making capacity. This can lead to restrictions of their liberty, to action being taken without their consent or despite their refusal and to other people doing what they believe is best for them on the grounds that they know better. Often this is based on assumptions that people with dementia do not understand the issues at stake (e.g. due to stereotypes that they are unable to understand the information provided or to assess risks), that other people are responsible for their

wellbeing (e.g. due to blanket labelling of people with dementia as vulnerable) and that other people's peace of mind justifies certain restrictions.

The gradual move away from an 'either/or' approach to decision making and legal capacity towards a more flexible, nuanced and supportive approach has been particularly noticeable in the context of guardianship measures, as well as in healthcare and research. Here, the concepts of shared and supported decision making are becoming increasingly common. It is now widely accepted that there is a moral imperative to involve people who lack decision-making capacity in decision making concerning their lives. This includes respect for human rights, which means recognising and protecting the dignity of all human beings, and ensuring that everyone is entitled to active, free and meaningful participation in, contribution to, and enjoyment of civil, political, economic, social and cultural development. This does not, however, rule out the need to sometimes make decisions on behalf of someone with dementia who, having been provided with all possible support, cannot make the decision needed.

Supported decision making

Recognition of legal capacity has long been dependent on an evaluation of decision-making capacity. This usually involves an assessment of whether a person is able to understand relevant information, apply it to their own life, decide freely/voluntarily and communicate their decision by whatever means possible for them. The aim of supported decision making is to provide the necessary support for someone to make a decision, and thereby retain and exercise their legal capacity, even though they would not have been considered capable of deciding in the absence of that support. Capacity assessments should therefore not be just to determine whether someone can decide autonomously or manage independently but rather to determine what kind of support they need and whether any support provided actually enables them to make their own decisions.

Supporters should advise and act according to the person's will and preferences, in keeping with the person's identity and respecting their right to take certain risks and to make decisions that other people might consider wrong. An over-emphasis on avoiding undue influence and an awareness of possible unequal power relations may sometimes lead to a kind of 'forced' autonomy, and to people not receiving the advice and support they need to make difficult decisions. The involvement of other people in decision-making is perceived as enhancing rather than impeding autonomy, and should therefore be actively promoted, albeit with necessary safeguards and transparency.

Shared decision making

Shared decision making, which can be part of supported decision making, challenges paternalistic attitudes and practices, and recognises the validity of the experience, views and preferences of the person directly concerned by a particular decision. It also reflects the concept of relational autonomy. Shared decision making is a more sophisticated approach than simply promoting the right to self-governance or the right to be left alone to make decisions. The aim is for people to find the best solution for themselves and for the people who matter to them.

In the context of healthcare, doctors are often best placed to know what the options are and which ones would be best for their patients, provided that they know their patients well and understand their values. Doctors therefore need to find out about their patients' values so as to be able to match those values with the medical facts relevant to each patient's situation. When done in the right manner (i.e. as a collaborative/shared exercise with patients and their families), this would not be paternalistic but rather a positive tool in medical communication. On the other hand, it should not be assumed that people all live in harmonious relationships or that the involvement of relatives necessarily promotes a person's autonomy, but it should be possible for people to be supported by significant others if they so wish.

Substitute decision making

If supported decision-making proves insufficient and all reasonably available resources for support have been exhausted, an authorised substitute decision maker should make a decision on someone else's behalf. The guiding question for substitute decision makers should not be what they personally prefer, nor what they would prefer if they were in the person's situation. Rather, it should be, "What would the person with dementia want in this situation if they had decision-making capacity?" In order of priority, sources of evidence of such will and preferences should include: (a) an advance directive, (b) previously communicated preferences with regard to the choice at hand and c) the person's values and commitments. A decision based on 'best interests' should only be made if all other sources of evidence about the person's will and preferences are unavailable or insufficiently clear.

4. Recommendations

Having the right to make decisions can have an impact on personal relationships, people's sense of identity and their perceived person/adult status, their quality of life and their ability to live according to their own values. The desire to behave in a way that is both legal and ethical raises many difficult questions and, in some cases, ethical dilemmas. Such dilemmas are not limited to the direct decision to be made but often play out at the level of society, reflecting an unfair system which does not provide the means to ensure that people with dementia have the opportunities as well the right to decide for themselves and to benefit from appropriate support where needed. Some sub-groups of the population, such as people with dementia from minority ethnic groups, with other medical conditions and disabilities and with lower levels of education or literacy, may be doubly at risk of their legal capacity being restricted and of lacking appropriate support.

The following are broad, overriding recommendations, which cut across different areas of life and situations in which the legal capacity of people with dementia should be recognised and supported, where possible, and where absolutely necessary, substitute decision making should take place.

1. It should be presumed that a person with dementia has legal capacity unless:
 - there is reason to suspect that the person's condition may be negatively affecting their decision-making capacity (not merely that they have a diagnosis of dementia) AND
 - all possible measures have been taken to support them to make a particular decision and this has not been successful.
2. Any restriction of legal capacity:
 - should be in relation to a specific decision or a specific area of decision-making (e.g. healthcare, independent living, personal finances etc.) because there is no all-purpose/global test of capacity,
 - should not be based on the assessment of a skill that a person has not yet acquired but may be capable of learning with time and support,
 - should not be more extensive/far-reaching than necessary,
 - should have been made after a legal or official procedure, recognised by the State and for which the person with dementia was involved and supported,
 - should be open to being challenged AND
 - should not be irreversible.
3. The provision of necessary, relevant and timely support, including where necessary substitute decision making, should be organised in a systematic and structured manner such as the combined supported decision-making model proposed by Scholten and Gather (2018).
4. People with dementia who lack legal capacity in relation to a particular decision or area of decision making (e.g. managing finances or making a will) should not be publicly labelled (e.g.

as ‘incapacitated’ or ‘incompetent’) or asked to reveal such information unless strictly necessary.

Alzheimer Europe’s full report contains a detailed discussion and recommendations for each of the following topics, which should be considered in addition to the above:

- Guardianship
- Treatment, care and support
- Communication of the diagnosis of dementia
- Advanced care planning and advance directives
- Participation in research
- Coercive measures (including formal restriction of freedom/involuntary placement, informal admission to residential care/involuntary stay and the use of restraint)
- Restrictions of freedom and the use of restraint during the COVID-19 pandemic
- Civil and political life (including voting, marriage and civil partnerships and making a will/testament).

6. References

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