

Kevin De Sabbata, Elena Syurina

# Supported Decision-Making and Dementia

Psychiatrie  
Verlag 

English extended version

German version in  
Martin Zinkler, Candelaria Mahlke, Rolf Marschner (Hg.)  
**Selbstbestimmung und Solidarität**  
Unterstützte Entscheidungsfindung  
in der psychiatrischen Praxis

Martin Zinkler, Candelaria Mahlke, Rolf Marschner (Hg.)  
Selbstbestimmung und Solidarität  
Unterstützte Entscheidungsfindung in der psychiatrischen Praxis  
1. Auflage 2019  
ISBN-Print: 978-3-88414-919-5  
ISBN eBook (PDF): 978-3-88414-971-7

English extended version of Kevin De Sabbata, Elena Syurina  
»Unterstützte Entscheidungsfindung und Demenz«, S. 25–45

Bibliografische Information der Deutschen Nationalbibliothek  
Die Deutsche Nationalbibliothek verzeichnet diese Publikation  
in der Deutschen Nationalbibliografie;  
detaillierte bibliografische Daten sind im Internet über  
<http://dnb.ddb.de> abrufbar.

Psychiatrie Verlag im Internet: [www.psychiatrie-verlag.de](http://www.psychiatrie-verlag.de)

© Psychiatrie Verlag GmbH, Köln 2019  
Alle Rechte vorbehalten. Kein Teil des Werks darf ohne Zustimmung  
des Verlags vervielfältigt, digitalisiert oder verbreitet werden.  
Typografiekonzeption: Iga Bielejec, Nierstein  
Satz: Psychiatrie Verlag, Köln

Dementia is a class of brain diseases causing, dependent on the subtype and single case, a progressive deterioration of cognitive abilities such as memory and reasoning coupled with problems of communication, changes in personality, sensory or motor impairments, and behavioural or psychotic symptoms (AMES, O'BRIEN & BURNS 2016). The WHO estimates that it currently affects around 50 million people worldwide (2016), of which around 10,5 million live in Europe (PRINCE et al. 2015), with 850.000 based in the UK (Alzheimer's Society 2014). In Germany, people with dementia are thought to be around 1,5 million (BÖHM, TESCH-ROMER & ZIESE 2009; OECD 2016) while in the Netherlands they appear to be more or less 250.000 (OECD 2016). Between 90 and 98 % are older individuals (over 65 years of age) as there is a strong correlation between aging and dementia (OECD 2015). Focusing on Europe, it is calculated that the condition affects around 1,5–2,5 % of the population aged 60–69, 3–7 % of that aged 70–79, around 8.5–20.5 % of that aged 80–89 and around 30–40 % of that aged above 90, with a consistently lower prevalence in the countries of Eastern Europe compared to Western Europe (PRINCE et al. 2015). However, 5 % of cases occur in younger individuals (Alzheimer's Society 2015 b).

Because of the seriousness of their impairments, people with dementia are often in need of medical and psychiatric treatment and of constant personal support, generating a significant burden of care and social/health care expenditure (ASH 2014). For these reasons, the question of how to guarantee appropriate person centred quality care to them is at the core of public debate and the agendas of governments in many western countries (WHO 2016). The symptoms of dementia may also contribute to create challenges for the person in engaging in decisions regarding their life and care. Indeed, it is not difficult to imagine how, for example, the impairment of memory could lead them to forget essential factual elements relating to a certain choice or how communication difficulties can be an obstacle to correctly understanding their will. Moreover, their right to choose is frequently hindered by the prejudice of medical and legal professionals, carers or common people who assume them incapable by default. It is also reduced by way of seeking their consent that does not take into consideration their information processing peculiarities (Alzheimer's Disease International 2012; Nuffield Council on Bioethics 2009).

Traditionally, the law has responded to these challenges by depriving the person of the possibility to directly make the decision, appointing a third

person (the guardian, caretaker or deputy) to choose for them (DHANDA 2006). However, a number of scholars have stressed the inadequacy of such an approach (QUINN 2010; HARDING 2012). Indeed, individuals with disabilities like dementia often maintain quite a strong ability to form motivated opinions about their life and care, so it appears unfair to disregard them and leave the choice to someone else (BARTH 2008; BEHUNIAK 2010; GATHER & VOLLMAN 2013). Due to these concerns, in the last decades the approach to legal decisions of people with mental disabilities like dementia is gradually shifting from substituting the person to assisting and empowering them to make choices for themselves. This movement has been promoted principally through Article 12 UN Convention on the Rights of Persons with Disabilities (CRPD), which centres on the concept of *supported decision-making*.

This article looks at the challenges of enabling people with dementia to make decisions on their medical and psychiatric care and how such challenges can be overcome through supported decision-making. In particular, it focuses on decisions on single treatments like medicines, surgical operations, or pharmacological and non-pharmacological mental health treatments. Therefore, it does not specifically look at choices regarding the person's hospitalisation, involuntary commitment, or end of life, though it does address some questions that may apply also to these areas. In its analysis, it refers to the principles established by Article 12 CRPD and to examples and promising practices developed in individual European countries. With regard to such initiatives, it has no aspiration to provide an exhaustive inventory of everything that has been established on the continent. Rather it aims to give some insights on what a support-based approach to legal decisions of people with dementia could look like in practice. Indeed, rather than provide step-by-step indications on how a person with dementia should be supported in each specific treatment decision, this contribution aims more to suggest general ideas on what supported decision-making in dementia care means and what the spirit should be on the basis of practices in this field.

In section two, a brief summary will be provided of the main characteristics of dementia as a pathological category, its symptoms, and its development. Then, section three will focus specifically on the obstacles and challenges faced by individuals with dementia in making choices on their life and care and on how such obstacles could be removed or attenuated if adequate support is given to the person. Section four will

focus on the idea of supported decision-making as it is framed in Article 12 CRPD. Section five will look at how supported decision-making can be practically realised, referring to cases and practices reported in white and grey literature. Finally, in the conclusion we will stress, both the advantages of this new approach and questions which still remain open.

## Dementia: symptoms and development

Dementia is an umbrella term describing several types of conditions affecting the cognitive functioning of an individual. Such conditions are characterized by a significant decline in one or multiple cognitive domains such as learning and memory, language, executive functioning, complex attention, perceptual-motor and social cognition. The deficit must interfere with independence in everyday activities, not occur exclusively in the context of delirium, and cannot be explained by the presence of other mental health conditions (APA 2013). The severity of symptoms and level of cognitive decline appear subject to fluctuations, sometimes on a daily basis, so that the person one day may appear completely lost and the following day seems generally able to reason or perform tasks (BRADSHAW, SALING, HOPWOOD, ANDERSON & BRODTMANN 2004). Moreover, the person with dementia may show changes of personality and opinions and challenging behaviour such as agitation, restlessness, aggressiveness, non-cooperative attitude, or apathy (ASH 2014). At the moment, there is no cure for dementia, so the condition has always a fatal *exitus* (WHO 2016).

According to KAUFER and DEKOSKY (2011), the various subtypes of dementia can broadly be divided into two categories: degenerative and non-degenerative dementias. While non-degenerative dementias represent a heterogeneous group of conditions with aetiologies varying from vascular and endocrine to inflammatory and nutritional ones (FLANAGAN 2015), the processes involved in the degenerative dementias are intrinsic to the nervous system depending on chemical alterations, the deterioration of synaptic processes, and atrophic phenomena (APA 2013). Examples of non-degenerative dementias include vascular dementia, posttraumatic dementia, and demyelinating disorders (FLANAGAN 2015),

while the main examples of degenerative dementia are Alzheimer's Disease and Dementia with Lewy Bodies (ASH 2014). Each dementia type has a unique pattern of symptoms. For instance Alzheimer's Disease is characterised by memory loss, while the initial symptoms of vascular dementia are more connected with personality changes (APA 2013). So, under the term »dementia«, various pathologies can be included with symptoms also quite different from one another. Moreover, the various forms of dementia may appear simultaneously in the same person, giving origin to cases of mixed dementia (Alzheimer's Association 2018). Beyond classifications, the way in which this condition manifests itself may vary significantly from person to person. This, together with the fact that its symptoms can be confused with physiological cognitive decline due to aging, make it often difficult to diagnose the condition, thus many people with dementia are never confirmed by their doctor as having it (APA 2013). Also for this reason, in the latest edition of the American Psychiatric Association Diagnostic Statistical Manual (DSM-5), the expression dementia has been substituted by »major neurocognitive disorder« (2013). However, the term is still widely used both in medical-scientific and public discourse, generally designating an acquired, persistent syndrome of cognitive impairment, often but not always linked to an increasing age and generally referring to widespread forms such as Alzheimer's disease, vascular dementia, dementia with Lewy-bodies and others (Ash 2014). This is mainly the use of the term to which we will also refer to in this article.

Alzheimer's disease (AD) and Dementia with Lewy bodies (DLB) are the most prominent examples of degenerative dementia conditions. Alzheimer's is supposedly linked to an increase in deposits of the protein fragment beta-amyloid (plaques) and twisted strands of the protein tau (tangles) (MASTERS 2016; RITCHIE & MASTERS 2016). The onset of AD is most commonly characterised by an impaired ability to form new memories (which includes short term memory loss, difficulties with learning and episodic memory) and decreasing visual memory (APA 2013). Individuals with these problems appear to struggle with remembering tasks and decisions in everyday life, forgetting appointments and being confused by planning changes. However, the presence of these symptoms alone is not sufficient. For the diagnosis of AD, the person has to have additional deficiencies in several functional domains, such as language, executive function, praxis, visuospatial, or constructional

capacities (APA 2013). One of the most frequent secondary deficiencies present in people with AD is the difficulty in word-finding and increasing rate of semantic approximation, which can arise from the impairment of semantic memory (MARTIN & FEDIO 1983). This means that the individual tends to use a more simplified language and struggles to find correct words to express their thoughts.

Regarding the onset and progression of the condition, each case is relatively unique, though it is standard to speak about two types of Alzheimer's: early and late onset (ROSSOR et al. 1984). The former type involves people under the age of 60–65, while the second and most prevalent involves people above that age. They are not only different in the time of the first symptoms appearing, but also have a distinct progression, with early onset having a stronger negative impact on attention and executive functioning as well as a quicker deterioration of the short-term memory (MARTIN & FEDIO 1983). This means that the individual can have quicker deterioration of the ability to focus and switch between tasks as well as general forgetfulness and difficulty keeping up with a schedule. However people with this condition tend to have well-preserved general memories about their past. Late onset individuals seem to show worse outcomes regarding their long-term memory and semantic abilities. Therefore, they have a quicker demise of memories of self as well as more difficulties remembering general knowledge about the world around them.

Dementia with Lewy bodies accounts for as much as 4.6 % of all dementia cases (KANE et al. 2018). It is caused by abnormal masses of alpha-synuclein protein in neurons, which impede synapses (MCKEITH 2007). The principal areas of cognition affected by DLB include attention, executive functioning, and visual perception, the latter specifically including colour vision impairment (MCKEITH 2006). The last aspect is the one more characteristic of Dementia with Lewy-Bodies in comparison with similar conditions such as Alzheimer's (FLANIGAN 2017). So people with this subtype of dementia, apart from having memory problems, difficulties with planning, organising, concentration, and switching between tasks, may also face issues with seeing objects and colours. Moreover, individuals with Dementia with Lewy Bodies are more likely to have problems with sleep and visual hallucinations. Other differences between DLB and AD include gender prevalence (with DLB being more prevalent and aggressive in men), significantly shorter course of the disease, and

prominent presence in DLB of other neurological signs such as slowness, imbalance and other Parkinsonisms (BARKER et al. 2002).

The other major category of dementing diseases is vascular dementia. The term is used to describe a broad range of impairments impacting on reasoning, attention, planning, and general judgement due to obstructed flow of blood to the brain. One of the most prominent examples of the group is Binswanger's disease, a small vessel vascular dementia caused by damages to the white matter areas (responsible for the transmission of impulses and communication between the various areas of the brain) (BABIKIAN & ROPPER 1987). Despite the fact that the condition is classified under the dementia umbrella, mood changes and neurological signs are its earliest signs and not cognitive deficits (BARKER et al. 2002). Binswanger's Disease is characterised by manic phenomena, obsessions, and fixation on ritualistic behaviours that severely impact the everyday functioning and eventually result in significant levels of personal neglect (LAWRENCE 2000). Aphasia and psychomotor problems are also often observed in persons with Binswanger's Disease, while memory impairments are less prominent (BARKER et al. 2002).

The heterogeneity of dementia's clinical manifestations makes it difficult to draw a general pattern with regard to the course and development of the condition. However, for practical reasons related to the management of the person's care, several scales have been developed aiming at assessing the severity of the symptoms and the rate of the general cognitive decline (FOLSTEIN et al. 1975; REISBERG et al. 1982). These tools give only a very general and often inaccurate representation of the dementia course so they often encounter the perplexity of experts. However, they may be useful to give a general idea of the condition progression. One of the most common classifications is the Clinical Dementia Rating (CDR) scale (HUGHS et al. 1982). This scale has four stages: no dementia, mild, moderate, and severe. Mild dementia is characterised by rare but persistent short-term memory loss (especially inability to remember the details and sequence of recent events), mild difficulty in solving everyday problems, especially complex ones for which concentration and memory are important, and mild difficulty with hobbies and community activities. Moderate dementia is observed when memory loss symptoms develop further, leading to the situation when only the most crucial, most emotionally weighted facts are retained. The individual can hardly live alone at home as they have a profound deterioration of cognitive functioning and ability to reason.



Another group of symptoms is linked to a narrowing field of hobbies and interests, which in part is due to the emotional state of the individual and in part to their inability to perform most of the tasks relating to previous hobbies. The final stage is severe dementia. In this stage, an individual cannot live at home and has to be under continuous supervision due to extreme memory damage and inability to make weighted decisions and perform activities of daily living. In the very final stage, they often seem completely unable to speak or interact with the environment around them, they need to be fed, and they cannot move from their bed.

Because of the described symptoms, people with dementia are often in need of supported living or relocation to specialised institutions where the daily care and support can be guaranteed. Moreover, they continuously require of medical and psychiatric treatment. Indeed, especially people with Alzheimer's take anti-cholinesterase drugs such as Donepezil, Rivastigmine and Galantamine (BREGMAN & MOORE 2014; FOX et al. 2014). These pharmacological daily treatments reduce memory loss or confusion, but may cause nausea, diarrhea, vomiting, anorexia, and weight loss. Moreover, individuals with dementia may also be administered other medicines such as antipsychotics for the control of behavioural symptoms (BANERJEE 2009), which however have significant side-effects including feelings of drowsiness, tremors, accelerated cognitive decline, stroke, and increased risk of death (BALLARD & CORBETT 2010). Both behavioural problems and cognitive deterioration can also be addressed through non-pharmacological interventions. These may consist of physical therapy or exercise, face-to-face or group psychotherapy, and various techniques of cognitive rehabilitation such as reminiscence therapy (i.e. triggering the recall of memories through a variety of stimuli), validation therapy (focusing on building sense confidence and self-respect), multi-sensory stimulation, speech therapy, music therapy, and support groups (BREGMAN & MOORE 2014). These interventions are surely less controversial and do not bear the side effects of drugs, but still have an impact on the everyday life of people with dementia, occupying part of their time, putting them in potentially uncomfortable situations, forcing them to enter in human relationships they would not have cultivated otherwise, or to perform activities they would have not done. Also, dementia appears associated with a significant number of comorbidities, that is other physical or mental health conditions arising congruently (BUNN et al. 2014; SANDERSON et al. 2002; SCHUBERT et al. 2006). In particular, the physical illnesses most frequently coinciding

with dementia appear to be cardiovascular and cerebrovascular diseases, diabetes, fractures often related to falls, osteoporosis, various visual and auditive impairments, cancer, Parkinson's disease, renal conditions, prostatic hypertrophy, and skin ulcers. In relation to psychiatric conditions the most prevalent are depression, bipolar, and delusional disorders (SCHUBERT et al. 2006). Therefore, people with dementia are very likely to face at least one serious surgical intervention such as a heart operation, cancer surgery, hip replacement, removal of compromised organs such as kidneys, or eye surgery. Moreover, they may have to take medications such as chemotherapy, drugs for preventing high pressure, angina, blood clots, arrhythmia and heart failure, or insulin, diuretics or again anti-psychotic medications; all treatments that can be invasive or present significant side effects spanning from confusion, blurred vision, dizziness or fainting, to fatigue, anemia, appetite changes, nausea and vomiting, increased risk of falls, difficulty urinating or diminished cognition (CURB 1996; OLIVER 2000; AYAN 2016). Therefore, giving and collecting the consent of people with dementia regarding these treatments is a common situation for the person, their careers and doctors.

## Challenges in making treatment decisions

All the symptoms described above can contribute to create significant challenges for the person in making decisions on their care. Due to memory loss, the individual with dementia may not remember crucial elements relating to a proposed treatment and struggle to understand what they have to decide on (FIELDS & CALVERT 2016; GATZ 2006; KIM et al. 2001). These gaps may appear quite extensive already in individuals with moderate dementia, so that they do not recall, for example, the purpose of a common medication, the side effects of a certain procedure, or how a procedure is performed. Moreover, people with this condition may not be up-to-date about the current state of medicine, which could make it tricky for them to understand certain information about medications and their effects.

Equally, the person may not remember both semantic facts and details of their own life, which can play a role in a range of decisions (CHARLAND 2011; DRANE 1985; GRISSO & APPELBAUM 1998). Indeed, as noted by

HOLM (2001), the loss of memory weakens the connection between the desires of people with dementia and reality, so that their wishes can be based on circumstances which do not exist or do not exist anymore (HOLM 2001). Therefore, the person might refuse to relocate to a nursing home or accept an invasive treatment due to a belief that they will be assisted in the recovery by their partner, who in reality has passed away. Especially in dementia with Lewy-bodies, another element contributing to the distance of the person from reality may be hallucinations. Indeed, as reported by MCKEITH (2017), such hallucinations are often well-formed, featuring people, children or animals, and depicting in the person's mind a parallel reality which conditions their choices.

Also, due to gaps in short-term memory and executive functioning, people with dementia may not even seem to realise that they need care or treatment in the first place (SNYDER 1995). Indeed, individuals with this condition can be unaware of their very memory problems, which impacts their ability to make conscious decisions about medications such as cholinesterase inhibitors (COSENTINO 2011). In other cases, involving especially individuals who had received an explicit dementia diagnosis, the consciousness of memory problems may have the effect of weakening the person's self-confidence, making them unsure of their opinions on treatment (GOODMAN et al. 2013). Moreover, these individuals may have a limited motive to deal with questions relating to their healthcare as they try to focus more on the present and on the positive aspects of their lives (BRONNER et al. 2016). Ignoring one's condition and a potentially scary future is a widespread coping mechanism adopted by people with dementia (DE BOER et al. 2007).

Another significant challenge in healthcare decision-making of people with dementia is related to the individual's difficulty in finding words and explaining their will. This problem is particularly felt by the person themselves, as evident from the statement of a man with this condition, reported by HULKO (2009 p. 163):

- » Well, having, um, a difficulty coming out with the right words for example or phrases or um having difficulty with, uh, numbers and, um, dates, times, um, having difficulty coming up with, um, difficulty, um, coming up with just a common expression, uh, or, um, even words that are very frequently used by anyone without the disease and um having difficulty coming up with just ordinary expressions. «

A woman with early stage Alzheimer's confesses: »I lose one word and then I can't come up with the rest of the sentence« (TRABERT 1997 p. 7). Another man says: »for a while I search for a word and I can see it walking away from me. It gets littler and littler. It always comes back, but at the wrong time« (SNYDER 1995 p. 694). Because of such issues, doctors, carers, or relatives may have difficulties understanding what the person wants in terms of medical treatment (LIVINGSTON 2010; BRONNER et al. 2016). Moreover, the conversation about a certain treatment choice may be made difficult by the person's deficit of attention, which leads them to lose the flow of the conversation even when minor distractions occur (SOUKUP 1996; KENNARD 2014).

Another element which may create issues in understanding the person's will regarding medical treatment comes from their tendency to change their ideas and seemingly contradict themselves. Indeed, individuals with dementia may often be unable to recall their previously expressed wishes or the reasoning and rationale beyond them. HOLM (2001) notes how their desires can be quite unstable, so if their attention is diverted even for a short period of time, they may forget needs that they once thought very important. Moreover, because of the fluctuations in their cognitive abilities, they may appear completely unable to participate in the moment in which a consultation is planned, while being perfectly lucid the day after (TRACHSEL, HERMANN & BILLER-ANDORNO 2015). All these dynamics create considerable uncertainties in the interpretation of the person's will and may push medical professionals towards choices conditioned by the fear of being accused of performing unconsented treatments rather than on the willingness to enact the person's own choice (HELMCHEN & LAUTER 1995; GALLAGHER & CLARK 2002; BENBOW et al. 1992).

Finally, individuals with dementia may be more exposed to undue influence and abuses (FELLOWS 1998; HORNING et al. 2013; FANG & YAN 2018). Indeed, feeling the sense of uncertainty deriving from their tendency to forget or to not grasp things, or the physical frailty due to their advanced age, they may be more disposed to agree to actions by relatives or spouses on whom they often rely (GALLAGHER & CLARK 2001). This tendency is indicated in this quote by a person with dementia, reported by BRONNER et al. (2016 p. 154):

- » My husband talks to the physicians and is more familiar with that. I was present during the consultation, but I wasn't able to participate actively.

I'm sitting nearby, half-involved. I haven't much knowledge, which my husband and the physicians have. «

However, though cognitive impairments definitely play a role in complicating the decision-making process, the problems reported above often seem to be triggered or aggravated by contextual factors, including stigma and prejudice, the way in which information on care is provided, and how decisions are made. Indeed, these problems could be substantially attenuated once adequate adjustments and aids are in place that help the person to recall memories, understand relevant information on their care or assist them in communicating their preferences (Deutsche Gesellschaft für Allgemeinmedizin und Familienmedizin 2008; TRACHSEL, HERMANN & BILLER-ANDORNO 2015; SOKOLOWSKI 2018).

Many people still see dementia only as a tragic and hopeless state in which the person is inevitably incapable and is left devoid of their self (SWINTON 2012; BEARD, KNAUSS & MOYER 2009). So, many medical professionals and informal carers often fail to consider involving the person even in simple decisions or they give up too soon in the attempt to aid the person to choose for themselves. Surveys show how more than 50 % of individuals with mild to moderate dementia tend to be judged by their doctors as unreliable and incapable of consent to medical treatment (CQC 2013; GILLIES 2001; MARSON 1997; MUELLER et al. 2015; WARNER et al. 2008). In fairness, a growing number of physicians are adopting a more nuanced and positive approach, but they still seem far from being the majority (HIRSCHMAN 2005). Also, these individual efforts are yet to have a measurable effect on the situation within dementia care. The Leeds Christian Council on Ageing (Nuffield Council on Bioethics 2009 p. 79) states: »We have noticed that it is too easily assumed by the decision makers in providing care (as well as generally) that people with dementia are incapable of making choices and taking decisions [...] thereby ›de-humanising‹ them.«

DERSE (1999) reports cases in which a surgical operation had to be performed on an individual with early stage Alzheimer's Disease and the surgeon avoided talking with the person about it, considering it more appropriate to discuss the details of the procedure only with the relatives.

Such beliefs are not innate to health care providers alone, as spouses and relatives also often have prejudices against their loved ones with

dementia and their ability to make decisions on treatment and care. In a study by MANTHORPE, SAMSI and RAPAPORT (2014 p. 136), a nurse reports: »Usually when we start having that conversation [carers] will say things like, ›well [my mum] doesn't know what she's doing, she can't make decisions«, even though this sort of scenario rather occurs only in the very late stages of the illness. Such negative attitudes are felt by individuals with dementia themselves. A person in the early stages of this condition, cited by PHILLIPS (2000 p. 2), remarked:

- » The reality is that when diagnosed with Alzheimer's, we are immediately discounted; our views are discredited because of the disease. «

DAVIS (1989 p. 91), in his personal account, denounces the risks others' attitudes pose for his autonomy: »I live with the imminent dread that one mistake in my daily life will mean another freedom will be taken from me«.

These prejudiced beliefs lead to the situation where medical professionals very rarely actively help the person in making decisions, for example explaining the information in simpler terms or reminding them of things they may not recall. They limit themselves to observe what they see at first sight, without asking what would happen if the person would be actually helped in understanding and reasoning on the implications of the proposed medication (MARSON 1997; MUELLER et al. 2015). This static approach to capacity assessment is also still at the basis of many national legislations, which do not contain norms requiring that, before declaring someone incapable, all possible efforts need to be undertaken to put them in the right condition to exercise their power of choice. Even those, like the English Mental Capacity Act 2005, which do contain such norms, (section 3) are often not faithfully applied with regard to this aspect.

In the last decades, in many European legal systems, legal capacity reforms have been enacted based on the principle that the person needs to be helped in making decisions rather than substituted. However, many of them leave still open the possibility that choices can be made for the person when support is not sufficient or when this is in line with their best interests. For example, the German Guardianship Law, which is strongly based on support rather than substitution, still allows, in § 1901, to overrule the wishes of the person, though in very limited circumstances. This leaves the door open to substitution when in reality the person seems to have an opinion of their own.

In addition, as noted by DONNELLY (2014), all legislations tend to consider decision-making of people with cognitive impairments like dementia only from the point of view of mental capacity. So they just look at whether the person has the necessary level of cognitive abilities to decide on their medical treatment. This ignores all other issues deriving from the context in which a certain decision takes place, which may be more impactful than the person's brain conditions.

Indeed, the decision-making process is often jeopardised by the fact that it often happens in noisy environments such as hospital wards or nursing homes, or while parallel conversations are taking place in the same room, a situation which makes it difficult for a person with dementia to intake information (BOUCHARD RYAN, BANNISTER & ANAS 2009). Moreover, COWDELL (2007) reports how care staff may tend to »bombard« their patients with dementia with information without giving them the time to realise what they have been told and using, in some cases, quite dismissive and even aggressive manners. Moreover, care staff or informal carers may not be adequately trained to communicate with people with dementia or to recognise their needs. In her empirical study, HARDING (2018 p. 148) reports the opinion of the informal carer of a woman with dementia complained that »in her first admission nursing staff seemed not to understand anything at all about dementia«. Another informal carer for a man with the same condition lamented »during his stay in hospital I visited my dad twice a day, this was because they did not understand his needs«.

Therefore, we need both a new legal model and a practice approach to medical decisions of mentally disabled individuals like people with dementia which empowers the person and helps them to overcome barriers they may face in making care choices.

## Supported Decision-Making and the UN Convention on the Rights of Persons with Disabilities

A decisive push towards such a system based on empowerment and support comes from Article 12 of the UN Convention on the Rights of Persons with Disabilities (CRPD). This norm focuses on legal capacity,

which is the construct enabling the law to recognise and validate personal legal decisions including choices on care and medical treatment (LEWIS 2011). Article 12 (1) CRPD affirms that all disabled people have »the right to recognition everywhere as persons before the law«. So, as noted by QUINN (2010), the Convention reaffirms how disabled individuals like people with dementia are not to be considered just as objects of care and charity but as *subjects, persons* with rights. From this statement derives the principle, contained in Article 12 (2) CRPD, according to which »States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life«. The norm promotes a true conceptual revolution, classifying legal capacity as a fundamental right, something no one can be deprived of (FLYNN & ARSTEIN-KERSLAKE 2014). Therefore, as stressed by the Committee on the Rights of Persons with Disabilities, the official body responsible for the monitoring of the CRPD implementation, »under article 12 of the Convention, perceived or actual deficits in mental capacity must not be used as a justification for denying legal capacity« (2014 p. 3). Therefore, under the Convention, the reaction of the law to issues arising in relation to cognitive impairments cannot be to strip the person of the power to directly make decisions, substituting them in the choice.

Instead, Article 12 (3) requires that »States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity«. General Comment No. 1 clarifies some key elements that must characterise supported decision-making (2014 p. 7). In summary, the Comment requires that:

1. the rights of the person are always respected and their will and preferences have primacy;
2. support measures are proportional to the person's needs and tailored to the concrete situation to which they are applied;
3. support should be available to everyone and costs, difficulties of communication and severity of impairment, should not be an obstacle to it;
4. legal capacity support »should not hinge on mental capacity assessments« or discriminatory indicators and requires the person's consent;
5. the person can refuse the support and there are safeguards to prevent abuses.

However, neither the Convention nor the General Comment provide a specific definition of supported decision-making. This leaves a series of



questions open. The first uncertainty relates to who should materially assist the person in making decisions. The Committee states that support »encompasses both informal and formal support arrangements« (2014 p. 4). In relation to both cases, it is necessary that the support person is a trusted individual who has a long term, ongoing relationship with the beneficiary and a good knowledge of the desires of the person (TRACY 2015; KEELING 2016; KNOX, DOUGLAS & BIGBY 2016). Informal arrangements, in which family members or friends voluntarily help the person on their request, emphasise this dimension of proximity, in addition to being less costly (CARNEY & BEAUPERT 2013; GOODING 2015; BIGBY 2017). Help may even be provided by more than one individual with differentiated roles forming a »circle of support« or »support network« (BACH & KERZNER 2010; DEVI 2013). Formal support arrangements would entail the appointment through a formal act (e.g. lasting power of attorney or authority decision) of a caretaker helping the individual in a series of choices (CARNEY & BEAUPERT 2013). As stated by GLEN (2013), such mechanisms can be very useful especially when the person lives alone and has no family, as is often the case with older people. Moreover, being formally appointed, the support person is usually subject to regular scrutiny by a designated body. Also in this case the role may be shared by a series of individuals. As suggested by the Committee, an important contribution may be given by independent advocates, who have the advantage of being external to the family, making them impartial and less inclined to exert pressure on the person (Committee on the Rights of Persons with Disabilities 2014 p. 4). As stated by Mirfin-Veicht, it can also take the form of peer advocacy/peer support or self-advocacy in which an individual with the same disability of the beneficiary helps him or her in making decisions (MIRFIN-VEICHT 2016; Committee on the Rights of Persons with Disabilities 2014 p. 4).

Another open question concerns the possible means of support that need to be put in place according to the CRPD. As all measures must be »tailored to the person's circumstances« (Article 12 (4)) it is difficult to identify them on an a priori basis. However, the Committee gives some examples. The first kind of support means it identifies consist of providing accessible information, reminding or explaining a certain point in simple terms (Committee on the Rights of Persons with Disabilities 2014 p. 4; MCDAID & DELANEY 2011). Another way of supporting the person may be through »the development and recognition of diverse,

non-conventional methods of communication« in the case of individuals who have difficulties in expressing themselves like many people with advanced dementia (TRACY 2015). It may also consist of creating a favourable or quieter environment (KEELING 2016). A third form of support identified in general Comment No 1 is advance care planning, which allows the person to clarify »will and preferences which should be followed at a time when they may not be in a position to communicate«.

Trying to provide a general definition of supported decision-making, the CRPD Handbook for Parliamentarians states that the support person(s) is or are someone who »explain(s) the issues when necessary, and interpret(s) the signs and preferences of the individual« and can, for example, »communicate the individual's intentions to others, help the person to understand the choices at hand« or »help others to realise that a person with significant disabilities is also a person with a history, interests and aims« (Office of the High Commissioner for Human Rights 2007).

## Support techniques for people with Dementia

These ideas have started being applied only quite late to the field of dementia (Dementia Alliance International 2016). Indeed, the movement promoting the adoption and implementation of the CRPD has mostly involved physically disabled individuals, individuals with psychosis or people with intellectual disabilities, tending to leave people with dementia at the margins. Therefore, we still do not have extensive indications from literature and practice, on how supported decision-making may work in this specific field.

However, some professionals, care structures, research institutions and charities are starting to put initiatives in place which are aimed at helping persons with this condition make choices on their care. Many of them are not directly triggered by the Convention, but are the result of the increased awareness, among single healthcare professionals, that the voice of these people should be heard more and that they could be empowered to have a more central role in the decision-making process on their treatment. In this sense some Dutch (GROEN-VAN DE VEN 2016;

MARIANI et al. 2017), British (LIVINGSTON et al. 2010; DALY, BUNN & GOODMAN 2016), Norwegian (SMEBYE, KIRKEVOLD, ENGEDAL 2016) and Italian (MARIANI et al. 2017) medical and research teams have approached these themes, mainly within the scheme of shared decision-making. This concept cannot be completely equated to that of supported decision-making. Indeed, as noted by SIMMONS and GOODING (2017), shared decision-making refers to a set of skills and practices that clinicians can use in order to involve their patients in healthcare decision-making processes, for reasons that may have to do with recognition of decisional power, but also with more pragmatic questions related to the efficacy of a certain therapy or ease in care management. On the other hand, supported decision-making is more specifically concerned with promoting the autonomy of disabled individuals and removing barriers to their decisional power. Therefore, it refers more widely to all the adjustments (even independent from the doctor) which can enable the person to make decisions. However, shared decision making certainly contains many elements which, in practice, can favour the empowerment and support of people with dementia in care decisions. Therefore, it represents a valid framework, more familiar to medical practitioners, to start implementing a support-based system of capacity to consent. Each of the cited experiences make use of triadic support networks made up by the person, their relatives and the doctor. In this regard, they have the advantage of providing an arrangement through which people that are around the person in question are able to use their action to support the individual, remind them of elements they may have missed, or to ease the communication process. Moreover, being based on more than one »supporter« they also reduce the risk of undue influence, as the different members of the support network can also check the action of others, preventing potential abusive behaviours.

Among these initiatives, particularly promising is the one carried out by MARIANI et al. (2017), in a Dutch and an Italian Nursing home. It includes a structured preliminary training session for healthcare professionals. The staff of the two structures involved was invited to take part in a communication skills course featuring elements of role-playing technique. Then, they conducted discussion sessions with people with dementia and their relatives drafted an agreed-upon care plan for the person. In this regard, the role of the family caregiver is described as especially important in understanding the needs of the person. However,

especially in the Italian context, there is often the risk that the family caregiver tries to substitute for the person. In this regard, an Italian professional affirms:

- » During some interviews, the family caregivers supported us and suggested issues to discuss. We have learnt a lot from them [...] But sometimes family caregivers want to substitute themselves to the residents, and answer in their place. This does not facilitate the discussion with residents. «

In these cases the care professional may counterbalance the disruptive action of the relative, as explained by another Italian nurse:

- » During one interview, the family caregiver wanted to focus on a topic that was different from the question addressed to the resident. However, the resident kept repeating the same answer, meaning that for her the topic was important. Thus, the psychologist reassured the resident, who consequently started feeling more at ease, that she had a leading role in the situation. In fact, [at the start of the interview] the resident was really agitated and had spasms, whereas, at the end, she was quiet and peaceful. The family caregiver then understood that the topic was important for her mother. «

The risk of undue interference and the importance of the balancing role of each member of the network is also stressed by SMEBYE, KIRKEVOLD and ENGEDAL (2016) in relation to the Norwegian context. However, the researchers admit that there are situations in which doctors and professional carers fail to challenge the preconceptions of family members. In this regard, an issue characterising all the experiences analysed so far is that the support network does not include an independent advocate, which promotes the will of the person in situations where professionals and family members share interests which are conflicting with that of the person. The opposite problem has come out in the Dutch context. Here it has emerged how sometimes family members are not willing to be involved in the support network, frustrating the process. However, with regard to the British context, Livingston shows that when the discussion within the support network is conducted properly and everyone is involved the result can be quite satisfactory (LIVINGSTON et al. 2010). In this context, a relative of a person with dementia affirmed:

» We weren't in agreement with each other ... whether to have a heart operation ... with hindsight ... it was the right decision ... he decided... it made his mental abilities much worse, but physically, he's much better. « (LIVINGSTON et al. 2010 p. 6)

With regard to specific support techniques, according to medical literature on shared decision-making, explanation and simplification are among the most important tools can be used to achieve a meaningful communication with the person interested in a certain treatment decision (EPSTEIN & STREET 2011). In this regard, a promising practise is the one developed in Norway by SMEBYE, KIRKEVOLD and ENGEDAL (2016). They have developed a shared decision-making procedure which provides that family members actively explain the information to the person and indicate how they have to proceed. The Norwegian researchers report that:

» Family carers and professional caregivers ensured that persons were informed and checked to make sure that they understood what the information meant in their situation. [...] Stating possible alternatives in a clear and concrete manner was at times necessary. Failing memory was compensated with aids/props to make options clearer. Narrowing the range of available choices because of limited powers of concentration and deliberation reduced confusion and promoted autonomous decision making. « ( p. 245).

The opinions of caregivers involved in the experience show that these techniques often lead to an improvement of the ability of the person to decide on medical treatment. However, there are also cases in which, despite the aid provided, the person appears unable to understand what was disclosed, as the cognitive impairment is too extensive.

Projects inside and outside the healthcare sector focus on providing accessible information to the person. This sort of practice is also endorsed by the Committee on the Rights of Persons with Disabilities which, among the possible forms of supported decision-making, mentions providing information in an understandable format (Committee on the Rights of Persons with Disabilities 2014). In this context, a praiseworthy initiative is the one promoted by the Dementia Engagement and Empowerment Project (DEEP) (2013), which published guidelines on how to write »dementia friendly information«. It provides a clear list of what

characteristics make a document more accessible. The guidelines are drafted by people with dementia themselves, ensuring that the principles affirmed truly match the needs of service users.

Tips provided by DEEP include

- presenting information »logically, one piece at a time«
- keeping language simple, writing concisely
- using quotations and examples in order to help the person understand the main points (2013 p. 2).

In addition, they suggest making use of pictures, distinguishing sections by using different colours, and using bold instead of italics.

In order to address issues of communication, a number of researchers have been focusing on how to build a more effective dialogue with the person, which can be carried on continuously day after day. MURAMOTO (2011) notes how the progressive nature of dementia requires viewing treatment decision-making as a process which goes on for several years during which the person's memories fade away. The researcher proposes that this loss of memories is counteracted by the relatives and close friends of the individual with dementia, who can act as »an external memory«, reminding the person of the elements they do not remember anymore (MURAMOTO 2011). This idea appears quite promising as it suggests a specific use of networks of support in order to solve one of the most urgent issues emerging in everyday practice. In addition, Smebye, Kirkevold and Engedal report an episode from their experience in a Norwegian nursing home, in which the carer acted as a reminder for the person in relation to daily personal care, saying, for example:

- » It is Friday today and on Fridays we have an agreement about showering. Look at your plan for the week written on your board. Come let me help you! « ( p. 247).

Apart from that, the idea of »external memory« has inspired many practices which use analogical or digital memory aids. CLARK and CHALMERS (1998) show how it can be very helpful for the person to keep a notebook, so they can record experiences, facts and notions, and can retrieve the information when needed. This arrangement is recommended by some charities (AlzSoc 2015).

Information technology permits going beyond simply sending reminders. Some groups of researchers have developed IT tools for supporting

people with dementia in the decision-making process. For example, an equipe of Dutch experts has developed DEcideguide, »an interactive web tool (in development) that case managers can use in facilitating shared decision-making in care networks of people with dementia« (SPAN et al. 2015). It consists of:

- a chat room in which the person with dementia can freely interact with other members of their support network,
- an application through which the members of the network can discuss the different stages of a certain decision, and
- a tool which permits to the person to isolate and analyse their feelings on certain aspects of their choice.

This programme can be very helpful, especially in case of younger people with dementia who have more familiarity with IT, for guaranteeing a constant interaction of the person with their support network. The team that created this tool is still working towards making it more accessible, following the advice of users themselves, who suggested simplification of the graphic interface and language used.

As noted by FRITSCHY, KESSELS and POSTMA (2004), the technological aids mentioned above open very promising avenues, especially with regard to the goal of providing better assistance to people living alone or in isolated areas. In particular, they can be of great help in relation to care decisions, since they may be used by the person to record their will on certain medications. However, they are often expensive and require a level of technological literacy which people with dementia often do not have because of their age. A possible way to solve this problem could be the modification of the interface of such tools. In addition to such issues, we need to consider that many of these applications imply the storage of a large amount of sensitive data, requiring that the person gives consent beforehand. As shown by BATCHELOR et al. (2012), making sure that a person with dementia, especially in an advanced stage, is really in the position to consciously consent to the use of their personal data could be extremely challenging.

Other researchers and charities are focusing on solving communication problems by creating a better environment for the person. In relation to his experience with older people in an Italian hospital, GIAMPIERI (2012) notes that supported decision-making may also consist of trying to overcome possible difficulties of communication. In this context,

doctors, nurses or relatives have to identify the moments in which the person appears more lucid, making them feel at ease during the conversation and assisting them with words or concepts that may not come to mind immediately. GIAMPIERI (2012) also focuses on the aspect of the interpretation of the person's will. In this context, the role of the supporter would consist of trying to resolve possible contradictions in the person's statements, even by asking him or her for further clarifications. Moreover, the supporter may also be required to identify the utterances which do not have to be taken into account, being the result of misunderstandings or moments of distress. Finally, the work of the interpreter may also include taking into account statements of the person which are not directly related to treatment decisions, but may nonetheless be useful for reconstructing the person's opinions.

## Conclusion

In summary, we have seen how many obstacles which, in practice, prevent people with dementia from deciding on medical treatment can be attenuated and overcome by adopting an approach based on supported rather than substituted decision-making. Indeed, doctors, carers and all the people around the individual with dementia may be of great help in reminding the person of informations they may not recall or in easing the communication process between them and their doctors. Moreover, presenting information on care with a language which is linear and accessible to the person with this condition is also helpful. This way of approaching care decisions of people with dementia is more respectful of their right to autonomy than substituted decision-making as it enables many individuals to continue to directly make treatment choices even in quite advanced stages of their condition.

The principles and practices reviewed in this article show how a more empowering approach to choices in dementia care is possible. However, they also leave many questions open. Indeed, we need to be aware that the reported initiatives, though promising, are still limited in number and extension, often being restricted to single care structures or circumscribed geographical areas. They also have been established quite recently and often have only a very partial evaluation of their concrete effectiveness.



Moreover, supported decision-making requires that around the person with dementia there is a network of individuals disposed to put time and effort in helping them, a circumstance which is increasingly rare, considering that older people in our society are more and more lonely. Finally, supporting the person in making care decisions surely requires medical professionals to dedicate more time to each patient, time which may be difficult to find in current hospitals and health systems characterised by resource constraints and understaffing. However, the promising practices discussed in this article show that such problems can be overcome or at least attenuated when the actors involved in the care of the person with dementia are really willing to do it.

All these challenges have not yet been fully addressed by literature also due to the fact that the interest for decisional support practices in dementia care is still relatively limited compared to other themes in dementia research. In this regard, we hope that our contribution, besides providing indications on how people with dementia may be empowered to better express their opinion on medical treatment, may stimulate future research in this field which is much needed.

## References

- Alzheimer's Association (2018): Mixed Dementia. Accessed: [www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/mixed-dementia](http://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/mixed-dementia) (9.7.2018).
- Alzheimer's Disease International (2012): World Alzheimer Report 2012: Overcoming the Stigma of Dementia, London: Alzheimer's Disease International.
- Alzheimer's Disease International and WHO (2012): Dementia. A Public Health Priority, Geneva: WHO Press.
- Alzheimer's Society (2014): Dementia UK Update. Alzheimer's Society, 43–59.
- Alzheimer's Society (2015): What is Dementia. Accessed: [www.alzheimers.org.uk/site/scripts/](http://www.alzheimers.org.uk/site/scripts/) (20.2.2017).
- Alzheimer's Society (2015 b): What is young-onset Dementia?. Alzheimer's Society. Accessed: [www.alzheimers.org.uk/about-dementia/types-dementia/younger-people-with-dementia](http://www.alzheimers.org.uk/about-dementia/types-dementia/younger-people-with-dementia) (20.2.2017).

- Alzheimer Society. (2015c): The Dementia Guide. Living Well after the Diagnosis. Accessed: [www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=2240&pageNumber=2](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2240&pageNumber=2) (31.11.2016).
- American Psychiatric Association (2013): Diagnostic and Statistical Manual of Mental Disorders (5th ed), Washington: American Psychiatric Association.
- AMES, D.; O'BRIEN, J. T.; BURNS, A. (eds.). (2016): Dementia, 5th ed., Boca Raton: CRC Press.
- ASH, E. L. (2014): What is Dementia? In: The Law and Ethics of Dementia. FOSTER, C.; HERRING, J.; DORON, I. (eds). Oxford: Hart Publishing.
- AYAN, M.; POTHINENI, N. V.; SIRAJ, A.; MEHTA, J. L. (2016): Cardiac Drug Therapy – Considerations in the Elderly, *Journal of Geriatric Cardiology*, 13: 12, 992 – 997.
- BABIKIAN, V. & ROPPER, A.H. (1987): Binswanger's Disease: A Review, *Stroke*, 18:1, 2–12.
- BACH, M. & KERZNER, L. (2010): A New Paradigm for Protecting Autonomy and the Right to Legal Capacity. Accessed: [www.lco-cdo.org/disabilities/bach-kerzner.pdf](http://www.lco-cdo.org/disabilities/bach-kerzner.pdf) (31.1.2015).
- BANERJEE, S. (2009): The use of Antipsychotic Medication for People with Dementia: Time for action (UK Department of Health). Accessed: <http://psychrights.org/research/digest/nlps/banerjeereportongeriatricneuroliticuse.pdf> (27.5.2018)
- BALLARD, C. & CORBETT, A. (2010): Management of Neuropsychiatric Symptoms in People with Dementia, *CNS Drugs* 24:9, 729–739.
- BARKER, W. W. et al. (2002): Relative Frequencies of Alzheimer Disease, Lewy Body, Vascular and Frontotemporal Dementia, and Hippocampal Sclerosis in the State of Florida Brain Bank, *Alzheimer Disease and Associated Disorders*, 16:4, 203–212.
- BARTH, L. (2008): Chronologie eines rechts- und verfahrensförmigen Sterbeprozesses. *Zeitschrift zum Altenpflegerecht*. Accessed: [www.openpr.de/news/269559/Chronologie-eines-rechts-undverfahrensoermigen-Sterbeprozesses.html](http://www.openpr.de/news/269559/Chronologie-eines-rechts-undverfahrensoermigen-Sterbeprozesses.html) (30.9.2019).
- BATCHELOR, R.; BROBOWICZ, A.; MACKENZIE, R.; MILNE, A. (2012): Challenges of ethical and legal responsibilities when technologies' uses and users change: social networking sites, decision-making capacity and dementia, *Ethics and Information Technology*, 14: 2, 99–108.

- BEARD, R. L.; KNAUSS, J.; MOYER, D. (2009): Managing Disability and Enjoying Life: How we Reframe Dementia through Personal Narratives, *Journal of Aging Studies*, 23, 227–235.
- BEHUNIAK, S. M. (2010): ›Toward a Political model of Dementia: Power as Compassionate Care‹, *Journal of Aging Studies*, 24: 4, 231–240.
- BENBOW, S. M.; JONES, R.; RANDS, G.; WATTIS, J. P. (1992): Mentally Incapacitated Adults and Decision Making: implications of the Law Commission consultation paper for old age psychiatrists, *Psychiatric Bulletin*, 16, 740–742.
- BIGBY, C. (2017): Delivering Decision Making Support to People with Cognitive Disability. What has been learned from Pilot Programs in Australia from 2010 to 2015, *Australian Journal of Social Issues*, 52:3, 222–240.
- DE BOER, M. E.; HERTOOGH, C. M.; DRÖES, R. M.; RIPHAGEN, I. I.; JONKER, C.; EEFSTING, J. A. (2007): Suffering from Dementia – the Patient’s Perspective: a review of the literature, *International Psychogeriatrics*, 19: 6, 1021–1039.
- BÖHM, K.; TESCH-RÖMER, C.; ZIESE, T. (eds) (2009): Beiträge zur Gesundheitsberichterstattung des Bundes Gesundheit und Krankheit im Alter, Berlin: Robert Koch-Institut.
- BOUCHARD RYAN, E.; BANNISTER, K. A.; ANAS, A. P. (2009): The Dementia Narrative: Writing to Reclaim Social Identity. *Aging Studies*, 23, 145–149.
- BREGMAN, N. & MOORE, O. (2014): Clinical Management of Dementia: an Overview (1). In: *The Law and Ethics of Dementia*. FOSTER, C.; HERRING, J.; DORON, I. (eds). Oxford: Hart Publishing.
- BRONNER, K.; PERNECZKY, K.; MCCABE, R.; KURZ, A.; HAMANN, J. (2016): Which Medical and Social Decision topics are important after Early Diagnosis of Alzheimer’s Disease from the perspective of People with Alzheimer’s Disease, Spouses and Professionals?, *BMC Research Notes*, 9, 149.
- BUNN, F.; BURN, A.; GOODMAN, C.; RAIT, G.; NORTON, S.; ROBINSON, L.; SCHOEMAN, J.; BRAYNE, C. (2014): Comorbidity and Dementia: a Scoping Review of the Literature, *BMC Medicine*, 12, 192.
- BRADSHAW, J.; SALING, M.; HOPWOOD, M.; ANDERSON, V.; BRODTMANN, A. (2004): Fluctuating cognition in dementia with Lewy bodies and Alzheimer’s disease is qualitatively distinct. *Journal of Neurology, Neurosurgery & Psychiatry*, 75 (3), 382–387.

- CARNEY, T. & BEAUPERT, F. (2013): Public and Private Bricolage: challenges balancing Law, Services and Civil Society in advancing CRPD Supported Decision-Making, *UNSW Law Journal*, 36, 175–202.
- CHARLAND, L. C. (2011): Decision-Making Capacity, *Stanford Encyclopedia of Philosophy*. Accessed: <https://plato.stanford.edu/entries/decision-capacity/#InfCon> (28.6.2018).
- CLARK, A. & CHALMERS, D. (1998): *The Extended Mind, Analysis*, 58: 1, 7–19.
- Committee on the Rights of Persons with Disabilities (2014): General Comment No. 1 (2014). Article 12: Equal recognition before the law' (CRPD/C/GC/1 eleventh session, 30 March–11 April 2014). Accessed: <https://daccess-ods.un.org/TMP/7283427.71530151.html> (26.1.2015).
- COSENTINO, S. et al. (2011): Memory Awareness Influences Everyday Decision Making Capacity about Medication Management in Alzheimer's Disease. *International Journal of Alzheimer's Disease*, Article ID 483897, <https://doi.org/10.4061/2011/483897>.
- COWDELL, F. (2007): The Care of Older People with Dementia in Acute Hospitals (2007). Accessed: <https://pdfs.semanticscholar.org/f2a7/f8e1ff4foe8d012a6f79c87c203cc9c02c56.pdf> (24.4.2018).
- CQC Care Quality Commission (2013): Time to Listen. In *NHS Hospitals. Dignity and Nutrition Inspection Programme 2012*, 14–18.
- CURB, J. B. (1996): Effect of Diuretic-Based Antihypertensive Treatment on Cardiovascular Disease Risk in Older Diabetic Patients with Isolated Systolic Hypertension, *Journal of American Medical Association*, 276: 23, 1886–1892.
- DALY, R.; BUNN, F.; & GOODMAN, C. (2016): Shared Decision-Making for People living with Dementia in Extended Care Settings: protocol for a systematic review, *British Medical Journal*, 6:11, e012955.
- DAVIS, R. (1989): *My Journey into Alzheimer's Disease*. Carol Stream: Tyndale House.
- DEEP (2013): Writing dementia-friendly Information. Accessed: <http://dementiavoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Writing-dementia-friendly-information.pdf> (21.2.2017).
- Dementia Alliance International (2016): *The Human Rights of People Living with Dementia: from Rhetoric to Reality*. Accessed: [www.dementiaallianceinternational.org/wp-content/uploads/2016/10/](http://www.dementiaallianceinternational.org/wp-content/uploads/2016/10/)

- The-Human-Rights-of-People-Living-with-Dementia-from-Rhetoric-to-Reality\_2nd-Edition\_July-2016\_English.pdf (16.6.2018).
- DERSE, A. (1999): Making Decisions about Life-Sustaining Medical Treatment in Patients with Dementia, *Theoretical Medicine*, 20: 1, 55–67.
- Deutsche Gesellschaft für Allgemeinmedizin und Familienmedizin (2008): Leitlinie Nr. 12: Demenz, Düsseldorf: Omikron.
- DEVI, N. (2013): Supported Decision-Making and Personal Autonomy for Persons with Intellectual Disabilities: Article 12 of the UN Convention on the Rights of Persons with Disabilities, *The Journal of Law Medicine and Ethics*, 41: 4, 792–806.
- DHANDA, A. (2006): Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future?, *Syracuse Journal of Law and Commerce*, 34: 1, 429–462.
- DONNELLY, M. (2014): A Legal Overview. In: *The Law and Ethics of Dementia*. FOSTER, C.; HERRING, J.; DORON, I. (eds). Oxford: Hart Publishing.
- DRANE, J. (1985): The Many Faces of Competency, *Hastings Center Report*, 15: 2, 17–21.
- EPSTEIN, R. M. and STREET, R. L. (2011): Shared Mind: Communication, Decision Making, and Autonomy in Serious Illness. *Annals of Family Medicine*, 9:5, 454–461.
- FANG, B. & YAN, E. (2018): Abuse of Older Persons With Dementia: A Review of the Literature, Trauma, Violence and Abuse, 19, 127–147.
- FELLOWS, L. K. (1998): Competency and Consent in Dementia, *Journal of the American Geriatric Society*, 46:7, 922–926.
- FIELDS, L. M & CALVERT, J. D. (2015): Informed Consent Procedures with Cognitively Impaired Patients: A review of ethics and best practices, *Psychiatry and Clinical Neurosciences*, 69, 462–471.
- FLANAGAN, E. P. (2015): Nondegenerative Dementias and Encephalopathies. In: *Mayo Clinic Neurology Board Review: Clinical Neurology for Initial Certification and MOC*, KD Flemming and LK Jones (eds), Mayo Clinic Scientific Press.
- FLANIGAN, P. M. (2017): Color Vision Impairment in Dementia with Lewy Bodies: A Novel and Highly Specific Distinguishing Feature from Alzheimer Dementia, *Alzheimer's & Dementia*, 13: 7, P1460.
- FLYNN, E. & ARSTEIN-KERSLAKE, A. (2014): The Support Model of

- Legal Capacity: Fact, Fiction or Fantasy?, *Berkeley Journal of International Law*, 32, 127–130.
- FOLSTEIN, M. F.; FOLSTEIN, S. E.; MCHUGH, S. R. (1975): Mini-mental state. A practical method for grading the cognitive state of patients for the clinician, *Journal of Psychiatric Research*, 12:3, 189–198.
- FOX, C.; CHEW-GRAMAH, C.; WOLVERSON, E.; MAIDMENT, I.; HILTO, A. (2014): *Clinical Management of Dementia: an Overview (2)*. In: *The Law and Ethics of Dementia*. FOSTER, C.; HERRING, J.; DORON, I. (eds). Oxford: Hart Publishing.
- FRITSCHY, E. P.; KESSELS, R. F.; POSTMA, A. (2004): External memory aids for patients with dementia: a literature study on efficacy and applicability, *Tijdschrift voor Gerontologie Geriatrie*, 35: 6, 234–239.
- GALLAGHER, P. & CLARK, K. (2002): The Ethics of Surgery in the Elderly Demented Patient with Bowel Obstruction, *Journal of Medical Ethics*, 28: 2, 105–108.
- GATHER, J. & VOLLMANN, J. (2013): Physician-Assisted Suicide of Patients with Dementia. A Medical Ethical Analysis with a special focus on Patient Autonomy, *International Journal of Law and Psychiatry*, 36: 5–6, 444–453.
- GATZ, M. (2006): Cognitive Capacities of Older Adults who are asked to Consent to Medical Treatment or to Clinical Research, *Behavioral Sciences and the Law*, 462, 466–468.
- GIAMPIERI, M. (2012): Communication and Informed Consent in Elderly People, *Minerva anesthesiologica*, 78 (2), 236–242.
- GILLIES, B. (2001): The Experience of Living through Dementia, *International Journal of Geriatric Psychiatry*, 16: 1, 111–112.
- GOODING, P. (2015): Navigating the »Flashing Amber Lights« of the Right to Legal Capacity in the United Nations Convention on the Rights of Persons with Disabilities: Responding to Major Concerns, *Human Rights Law Review*, 15, 45–71.
- GOODMAN, C.; AMADOR, S.; ELMORE, N.; MACHEN, I.; MATHIE, E. (2013): Preferences and Priorities for ongoing and End-of-Life Care: A Qualitative Study of Older People with Dementia resident in Care Homes, *International Journal of Nursing Studies*, 50: 12, 1639–1647.
- GRISSE, T. & APPELBAUM, P. A. (1998): *The Assessment of Decision-Making Capacity: A Guide for Physicians and Other Health Professionals*. Oxford: Oxford University Press.

- GROEN-VAN DE VEN, L.; SMITS, C.; SPAN, M.; JUKEMA, J.; COPPOOLSE, K.; DE LANGE, J.; EEFSTING, J.; VERNOOIJ-DASSEN, M. (2016): The challenges of shared decision making in dementia care networks, *International Psychogeriatrics*, 30: 6, 843–857.
- HARDING, R. (2012): Legal Constructions of Dementia: Discourse of Autonomy at the Margins of Capacity, *Journal of Social Welfare and Family Law*, 34:4, 437–440.
- HARDING, R. (2018): *Duties to Care. Dementia, Relationality and the Law*. Cambridge: Cambridge University Press.
- HELMCHEN, H. & LAUTER, H. (eds.) (1995): *Dürfen Ärzte mit Demenzkranken forschen?* Stuttgart: Thieme.
- HIRSCHMAN, K.; JOYCE, C. M.; JAMES, B. D.; XIE, S. X.; KARLAWISH, J. (2005): Do Alzheimer's Disease Patients Want to Participate in Treatment Decision, and Would their Caregivers Let Them?, *The Gerontologist*, 45: 3, 381–388.
- HOLM, S. (2001): Autonomy, Authenticity, or Best Interest: Everyday Decision-Making and Persons with Dementia, *Medicine, Health Care and Philosophy*, 4: 2, 153–159.
- HORNING, S. M.; WILKINS, S.; DHANANI, S.; HENRIQUES, D. (2013): A Case of Elder Abuse and Undue Influence: Assessment and Treatment from a Geriatric Interdisciplinary Team, *Clinical Case Studies*, 12, 373–387.
- HUGHES, C. P.; BERG, L.; DANZIGER, W. L.; COBEN, L. A.; MARTIN, R. L. (1982): A new clinical scale for the staging of dementia, *British Journal of Psychiatry*, 140: 566–572
- HULKO, W. (2009): From ›not a big deal‹ to ›hellish‹: Experiences of older people with dementia, *Journal of Aging Studies*, 23: 3, 131–144.
- KANE, J. P. et al. (2018): Clinical Prevalence of Lewy Body Dementia, *Alzheimer's research & Therapy*, 10: 19, 1–8.
- KAUFER, DANIEL & DEKOSKY, STEVEN (2011): Diagnostic Classifications: Relationship to the Neurobiology of Dementia. 895–907
- KENNARD, C.: Talking to People with Dementia, Accessed: [www.alzheimers.about.com/od/frustration/a/talking\\_dementi.htm](http://www.alzheimers.about.com/od/frustration/a/talking_dementi.htm) (7.11.2014).
- KIM, S.; CAINE, E. D.; CURRIER, G. W.; LEIBOVICI, A.; RYAN, J. M. (2001): Assessing the Competence of Persons with Alzheimer's Disease in Providing Informed Consent for Participation in Research, *American Journal of Psychiatry*, 158: 5, 712–717.

- KNOX, L.; DOUGLAS, J. M.; BIGBY, C. (2016): Becoming a Decision-Making Supporter for Someone with Acquired Cognitive Disability following Traumatic Brain Injury, *Research and Practice in Intellectual and Developmental Disabilities*, 3, 12–18.
- LAWRENCE, R. M. (2000): Is the Finding of Obsessional Behaviour Relevant to the Differential Diagnosis of Vascular Dementia of the Binswanger Type?, *Behavioural Neurology*, 12: 3, 149–154.
- LEWIS, O. (2011): Advancing Legal Capacity Jurisprudence. *European Human Rights Law Review*, 6, 700–714.
- LIVINGSTON, G. et al. (2010): Making Decisions for People with Dementia who Lack Capacity: qualitative study of family carers in UK, *British Medical Journal*, 341, c4184–c4193.
- MANTHORPE, J.; SAMSI, K.; RAPAPORT, J. (2014): Dementia Nurses' Experience of the Mental Capacity Act 2005: A follow-up study, *Dementia*, 13: 1, 131–143.
- MARIANI, E.; VERNOOIJ-DASSEN, M.; KOOPMANS, R.; ENGELS, Y.; CHATTAT, R. (2017): Shared Decision-Making in Dementia care planning: barriers and facilitators in two European countries, *Aging Mental Health*, 21: 1, 31–39.
- MARSON, D. C. (1997): Consistency of Physician Judgments of Capacity to Consent in Mild Alzheimer's Disease, *Journal of the American Geriatric Society*, 45: 4, 453–457.
- MARTIN, A. & FEDIO, P. (1983): Word Production and Comprehension in Alzheimer's Disease: The breakdown of semantic knowledge, *Brain and Language*, 19: 1, 124–141.
- MASTERS, C. L. (2016): The Neuropathology of Alzheimer's Disease. In: *Dementia* (5th Ed.) AMES, D.; O'BRIEN, J. T.; BURNS, A., Boca Raton: CRC Press.
- MASTERS, C. L. & BEYREUTHER, K. (1995): Molecular Neuropathology of Alzheimer's Disease, *Arzneimittelforschung*, 45: 3A, 410–412.
- MCDAID, S. & DELANEY, S. (2011): A Social Approach to Decision-Making Capacity: exploratory research with People with Experience of Mental Health Treatment, *Disability and Society*, 26, 729–742.
- MCKEITH, I. G. et al. (2006): Consensus Guidelines for the Clinical and Pathologic Diagnosis of Dementia with Lewy Bodies (DLB), *Neurology*, 47, 1113–1124.
- MCKEITH, I. G. (2007): Dementia with Lewy Bodies, *Handbook of Clinical Neurology*, 84, 531–548.



- McKEITH, I. G. et al. (2017): Diagnosis and Management of Dementia with Lewy Bodies. Fourth Consensus Report of the DLB Consortium, *Neurology*, 89: 1, 88–100.
- MIRFIN-VEICHT, B. (2016): Exploring Article 12 of the United Nations Convention on the Rights of Persons with Disabilities: An Integrative Literature Review. Dunedin: Donald Beasley Institute.
- MUELLER, T.; HABERSTROH, J.; KNEBEL, M.; OSWALD, F.; WEYGANDT, M.; SCHRODER, J.; MARKWORT, S.; PANTEL, J. (2015): Comparison of Three Different Assessments of Capacity to Consent in Dementia Patients, *Journal of Gerontopsychology and Geriatric Psychiatry*, 28, 21–29.
- MURAMOTO, O. (2011): Socially and Temporally extended End-of-Life Decision-Making process for Dementia Patients, *Journal of Medical Ethics*, 37: 6, 339–343.
- Nuffield Council on Bioethics (2009): *Dementia: Ethical Issues*, London: Nuffield Council on Bioethics.
- OECD (2015): *Addressing Dementia: The OECD Response*, OECD Publishing.
- OECD and European Commission (2016): *Health at a Glance: Europe 2016 – State of Health in the EU Cycle*: OECD Publishing, Paris.
- Office of the High Commissioner for Human Rights (2007): *From Exclusion to Equality. Realizing the Rights of Persons with Disabilities*. In: *Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities and its Optional Protocol*. Geneva: United Nations.
- OLVER, I. (2000): Chemotherapy for Elderly Patients with Advanced Cancer: is it worth it?, *Australian Prescriber*, 23, 80–121.
- PHILLIPS, J. M. (2000): A Personal View of Living with Early-Onset Alzheimer's, *Perspectives – A Newsletter for Individuals with Alzheimer's Disease*, 6, 1–2.
- PICKERING FRANCIS, L. (2001): Decision-Making at the End of Life: patients with Alzheimer's or other Dementias, *Georgia Law Review*, 35: 2, 539–592.
- POBLADOR-PLOU, B.; CALDERÓN-LARRAÑAGA, A.; MARTA-MORENO, J.; HANCCO-SAAVEDRA, J.; SICRAS-MAINAR, A.; SOLJAK, M.; PRADOS-TORRES, A. (2014): Comorbidity of Dementia: a Cross-Sectional Study of Primary Care Older Patients, *BMC Psychiatry*, 14: 84, 86–89.

- PRINCE M. et al. (2015): World Alzheimer Report 2015. The Global Impact of Dementia. Alzheimer's Disease International 2015, 1–92.
- QUINN, G. (2010): Personhood and Legal Capacity. Perspectives on the Paradigm Shift of Article 12 CRPD, HPOD Conference, Harvard Law School, Cambridge Mass. Accessed: [www.nuigalway.ie/~fcdlp/documents/publications/FHarvard%20Legal%20Capacity%20ogq%20draft%202.doc&ei=kqVXVIPPgZelAP3SguAP&usq=AFQjCNFaq5CV05onWjYovnAMvdKsRo3mGA&sig=yPXGGjEC-KgpQH2EP2dc7Q&bvm=bv.78677474,d.d2s](http://www.nuigalway.ie/~fcdlp/documents/publications/FHarvard%20Legal%20Capacity%20ogq%20draft%202.doc&ei=kqVXVIPPgZelAP3SguAP&usq=AFQjCNFaq5CV05onWjYovnAMvdKsRo3mGA&sig=yPXGGjEC-KgpQH2EP2dc7Q&bvm=bv.78677474,d.d2s) (25.2.2018).
- REISBERG, B.; FERRIS, S. H.; DE LEON, M. J.; CROOK, T. (1982): The global deterioration scale for assessment of primary degenerative dementia, *American Journal of Psychiatry*, 139: 9, 1136–1139.
- RITCHIE, C. W. & MASTERS, C. L. (2016): The Central role of A $\beta$  amyloid and tau in the Pathogenesis of Alzheimer's Disease. In: *Dementia* (5th Ed.) AMES, D.; O'BRIEN, J. T.; BURNS, A. Boca Raton: CRC Press.
- ROSSOR, M. N.; IVERSEN, L. L.; REYNOLDS, G. P.; MOUNTJOY, C. Q.; ROTH, M. (1984): Neurochemical Characteristics of Early and Late onset types of Alzheimer's Disease, *British Medical Journal*, 288: 961–964.
- SANDERSON, M. et al. (2002): Co-Morbidity associated with Dementia, *American Journal of Alzheimer Disease and Other Dementias*, 17: 2, 73–78.
- SCHUBERT, C. C.; BOUSTANI, M.; CALLAHAN, C. M.; PERKINS, A. J.; CARNEY, C. P.; FOX, C.; UNVERZAGT, F.; HUI, S.; HENDRIE, H. C. (2006): Comorbidity Profile of Dementia Patients in Primary Care: are they Sicker?, *Journal of American Geriatric Society*, 54: 1, 104–109.
- SIMMONS, M. B. & GOODING, P. (2017): Spot the difference: shared decision-making and supported decision-making in mental health, *Irish Journal of Psychological Medicine*, 34, 275–286.
- SMEBYE, K. L.; KIRKEVOLD, M.; ENGEDAL, K. (2016): Ethical dilemmas concerning autonomy when persons with dementia wish to live at home, *BMC Health Services Research*, 12, 21–33.
- SNYDER, L. et al. (1995): Supportive Seminar Groups: and Intervention for Early Stage Dementia Patients, *The Gerontologist*, 35, 691–694.

- SOKOLOWSKI, M. (2018): *Dementia and the Advance Directive: Lessons from the Bedside*. Berlin: Springer.
- SOUKUP, J.E. (1996): *Alzheimer's Disease: a guide to treatment, diagnosis, and management*. Westport: Praeger.
- SPAN, M.; SMITS, C.; JUKEMA, J.; GROEN-VAN DE VEN, L.; JANSSEN, R.; VERNOOIJ-DASSEN, M.; EEFSTING, J.; HETTINGA, M. (2015): Developing a Supportive Tool to Facilitate Shared Decision-Making in Dementia, *Frontiers in Aging Neuroscience*, 7, 253.
- STANLEY, B. (1983): Senile Dementia and Informed Consent. *Behavioral Sciences and the Law*, 57, 61–62.
- SWINTON, J. (2012): *Dementia: Living in the Memories of God*. Grand Rapids: Eerdmans Publishing Company.
- TRACHSEL, M.; HERMANN, H.; BILLER-ANDORNO, N. (2015): Cognitive Fluctuations as a Challenge for the Assessment of Decision-Making Capacity in Patients with Dementia, *American Journal of Alzheimer's Disease and Other Dementias*, 30: 4, 360–363.
- TRABERT, M. (1997): The DRC Club, Perspectives – A Newsletter for Individuals with Alzheimer's Disease 7, 7.
- TRACY, J. (2015): Supporting Nick to Make Decisions: An Exploration of Ways to Promote Choice and Control, *Research and Practice in Intellectual and Developmental Disabilities*, 2, 29–36.
- WARNER, J.; MCCARNEY, R.; GRIFFIN, M.; HILL, K.; FISHER, P. (2008): Participation in Dementia Research: Rates and Correlates of Capacity to give Informed Consent, *Journal of Medical Ethics*, 34: 3, 167–170.
- WHO (2016): *Dementia. Fact Sheet 362*. Accessed: [www.WHO.int/mediacentre/factsheets/fs362/en/](http://www.WHO.int/mediacentre/factsheets/fs362/en/) (20.2.2017).