

## GUEST EDITORIAL

# Decisional capacity: toward an inclusionary approach

### Introduction

Capacity, defined as the ability to make one's own decisions, has traditionally been seen as a dichotomous or categorical construct. People either have capacity, and are therefore afforded autonomy, or they lack capacity, and are therefore provided with a proxy decision-maker. In a way this concept – and the related practice of conceptualizing capacity as an all or nothing phenomenon – resembles the situation of Kafka's protagonist Gregor Samsa in *Metamorphosis* (1972 (in German 1915)). The opening lines of this breathtaking essay are world famous. In English they run as follows: "As Gregor Samsa awoke one morning from uneasy dreams he found himself transformed in his bed into a gigantic insect." As a consequence of this categorical change, Gregor is excluded and despised of. He is no longer considered an agent and ends up squashed by apples by his own relatives.

Although the parallel may seem far-fetched, the atmosphere of estrangement and alienation resembles what can happen to people who are diagnosed with dementia or other mental disorders, when suddenly their health professionals turn to their relatives to make healthcare and other decisions and they themselves are no longer afforded a role – read for example Maarten's experience in Bernlef's novel *Out of Mind* (1989 (in Dutch 1984)).

Fortunately, this situation is changing and we are moving toward a more sophisticated approach, away from a categorical and exclusionary practice toward a more dimensional and inclusionary concept of capacity. One of the fundamental ideas underlying this alternative approach is that capacity assessments should primarily be undertaken not to judge whether people are capable or not to decide "autonomously," but rather to assess what kind of support people with decision-making disabilities (DMD) need in order to be involved in decision-making and thus to promote their autonomy.

This paradigm shift has been heralded by a number of human rights frameworks such as the European Convention on Human Rights and the United Nations Convention on the Rights of People with Disabilities (UNCORPD, 2012). These conventions promote autonomy and the enjoyment of equal recognition before the law for people with disabilities, thus underscoring the right of people

with disabilities to enjoy legal capacity on an equal basis with other members of society. Importantly, UNCORPD Article 12 (2012) specifically recommends that signatories "take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity."

This obligation translates into a major challenge for healthcare and legal professionals alike. How do we support maximum participation in decision-making for those who lack decisional capacity? Some years ago, Beltram (1996) summarized the challenge of accurately assessing decisional capacity, referring to the usefulness of "pragmatic models of shared decision-making." However, there is no consensus yet as to how models of supported decision-making might be utilized by people with DMD.

In this contribution we propose a practical model for supported decision-making, which is inclusionary and founded in ethical and human rights frameworks. To this end we will first discuss how the ethical concept of autonomy has evolved during the past decades and how changing views on autonomy relate to support in decision-making.

### The concept of autonomy and its evolution

The rise of autonomy in bioethics and health law dates back to the 1970s and is closely linked with the movement for patient rights and criticism of medical paternalism. It is important to note, however, that this "new kid on the block in medical ethics" – to quote Faden and Beauchamp (1996, p.94 *et passim*) – was introduced without proper guidance, nor was it preceded by relevant empirical research on what patients expect from their physicians when it comes to health-related decision-making. Instead, the plea for a central role of autonomy in medical ethics was largely based on philosophical and legal arguments under the assumption that the right to independent choice would be welcomed and embraced by all patients.

This, however, was not exactly what happened. What did happen was that physicians increasingly marginalized their role in the decision-making process, restricting themselves to objectively presenting patients with options and odds, while

withholding their own experience and recommendations out of fear of overly influencing patients (Quill and Brody, 1996). This attitude was based on the assumption that the physician's exercise of power and influence inevitably compromises the patient's freedom of choice and thus discourages active persuasion by the physician in the face of differences of opinion between physician and patient (Quill and Brody, 1996). As a result, however, patients more or less felt that mandatory autonomy was posed upon them; what they missed was the provision of advice and adequate support from their health professionals in making difficult decisions (Loewy, 2005; Kim, 2010).

In the course of the 1990s, new ethical discourses on the role of autonomy, which were more inspired by empirical research into patient perspectives, began to gain ground. It became clear that, in moving from the paternalistic model to the independent choice model, medical ethics had wrongly, and not for the patient's benefit, endorsed a form of stark autonomy as the highest value (Loewy, 2005). The effect of this move away from the paternalistic model was that the perils of coercion were avoided at the cost of exposing the patient to the perils of abandonment. It became clear that a new balance had to be sought, based on a more nuanced approach of autonomy (Kon, 2009).

Relevant to this search for a new balance are studies that try to reconcile the principle of respect for autonomy with real life situations of human (inter)dependency. Thus, authors like Agich (1993; 2003), Taylor (1997), and Tronto (1993), writing from different but affiliated philosophical perspectives, have called attention to the relational aspects of autonomy. Agich and Taylor distinguish between negative and positive concepts of autonomy, and Tronto stresses the relevance of the caregiving relationship in promoting autonomy. By focusing exclusively on negative autonomy in terms of non-interference, medical ethics tends to reduce respect for autonomy to merely offering patients the opportunity for self-governance and allowing them "a right to be left alone" (Agich, 2003, p. 25). This negative conceptualization of autonomy reflects the human condition in a very distorted way. Specifically, it neglects our interdependency. People are neither born as self-governing individuals nor can they flourish as a person without the support of others. Our autonomy is always relative and has relevant relational and developmental aspects.

These are referred to in positive concepts of autonomy. For example, when it is said that autonomy means living life according to standards we can call our *own*, reference is made to a process of identification and of *becoming* (i.e., evolving), which underscores that people do not live their life isolated

from the world and its uncertainties. On the contrary, people regularly have to adapt in order to hold on to a sense of self, notably in relation to important life events and in adverse circumstances such as illness. And in doing so, they are in need of others to support them. A positive concept of autonomy further allows for degrees of autonomy and underscores, when it comes to (complex) decision-making, that providing support in arriving at a decision, for people with or without capacity alike, is not only necessary but can be achieved without imposing one's will. What decision support specifically aims at is guiding and allowing the other/patient to arrive at a decision he or she can identify with (Agich, 1993; 2003; Tronto, 1993), retaining ownership of the decision.

A decision-making model that has been suggested to align with this approach to autonomy is shared decision-making. However, before examining the appropriateness of this model in the specific context of people with DMD, two additional concepts need mentioning, both of which are relevant when it comes to finding the proper balance between coercion and abandonment in supported decision-making. The first one is the concept of *dignity of risk*. The second is the concept of *assent*.

### Dignity of risk

This concept originated in the movement for the deinstitutionalization of the developmentally disabled in the 1970s. It is promoted by the UN-CORPD (2012) and supports the right of individuals to choose to take some risk in engaging in life experiences. In terms of health and treatment/welfare decisions, dignity of risk requires complex but often necessary considerations to be made, balancing the autonomy of the individual and their rights to engage in otherwise normal life experiences on one hand, with that of duty of care owed to them by the health professional. In other words: adequate decision support must allow for a certain "right to take risks" instead of taking a strict safety-oriented and risk-averse stance.

### Assent

The concept of assent in healthcare was derived from ethical discourse in relation to terminally ill children and their right to contribute to decisions regarding their bodies and treatment. The concept of assent distinguishes approval, or a positive and voluntary agreement, from the concept of consent, which is voluntary but requires capacity. Assent refers to approval of a decision by a person lacking capacity who is not able to manipulate information relevant to that decision. Molinari *et al.* (2004) adapted the concept of assent to older persons lacking

substantial decision-making capacity. In their view, a finding of impaired capacity increases the likelihood that the patient will be excluded completely from the decision-making process. Their concept of geriatric assent calls upon physicians and concerned proxies or substitute decision-makers to elicit the preferences of older patients lacking capacity, and to try to gain their affirmation for healthcare decisions.

From the viewpoint of medical ethics, the strategy of seeking assent through soliciting expressions of patient's preferences and weighing them in the decision-making process treads the middle ground between rigidly respecting (negative) autonomy and paternalism. As such, it can be seen as an example of how autonomy can be promoted, in a way that is consistent with a positive approach to autonomy, because it entails a serious effort to allow patients to identify with the decision at hand and thus to make the decision also "theirs." It does not, however, teach us how to do this and what decision-making model is most appropriate.

### Shared decision-making

Shared decision-making can be defined as a joint process of decision-making between care professionals and patients (Brock, 1991; Briss *et al.*, 2004). This concept is based on a relationship between the health and social care professional and the patient, such that the health and social care professional helps the patient understand the various options available for the proposed care/treatment (including the pros and cons of each option); makes recommendations to the patient; and helps the patient base their preference on the best evidence available (Briss *et al.*, 2004). **This process occurs with reference to what is of value to the patient.** In this model, both the health and social care professional and the patient "lay all their cards on the table" with regard to the proposed treatment, and then work together to reach a consensus on the preferred treatment plan.

This model also gives room for patients and physicians to actively exchange ideas, negotiate differences, and share power and influence to best serve the patient's needs. Ideally, the healthcare professional/patient relationship should be such that the patient, empowered by the care professional, plays a maximum part in decisions relating to their care and treatment. Indeed studies have shown that a good proportion of patients would prefer this approach when decisions need to be made about their care (Deber *et al.*, 1996).

At face value, the concept of shared decision-making is very attractive and seems a very natural

way of arriving at a joint decision. However, its translation to everyday clinical practice is not self-evident. Often there are time constraints that limit the application of shared decision-making; further, there is a tendency among patients to be less willing to play an active role in decision-making as their illness increases in severity (Charles *et al.*, 1997; Gravel *et al.*, 2006). Finally, patient participation is highly dependent on cognitive abilities. By definition, the concept of shared decision-making relies on an equal participation between patients and physicians and thus has more relevance to patients with capacity, although many of the principles have application to patients lacking capacity.

### Collaborative decision-making

The concept of collaborative decision-making has been proposed not as an alternative model to shared decision-making but as a complementary approach to what can, in essence, be shared in an ongoing health or social care relationship in which decisions have to be made and acted upon (O'Grady and Jadad, 2010). Although protagonists of shared decision-making might be critical here and contend that *collaborative* decision-making merely expands on what is already included in *shared* decision-making, we believe that it is a more flexible model that still respects principles of autonomy while making way for different degrees of patient participation determined by variable patient willingness *or* cognitive ability.

Collaboration is a step beyond merely obtaining assent. Collaborative decision-making focuses less on the *who* of the decision-making process, but more on the *how* as well as on the *why* of patients wanting to make a particular decision. Arriving at decisions through collaboration involves knowledge building that goes beyond clinical issues through shared learning and compromise. Here the physician informs the patient about the treatment options at stake, while the patient is invited to inform the physician about what goes on in their life, what their values are, and their goals, thereby articulating non-medical factors that are meaningful and contribute to their identity. The treatment decision is thus reframed within this wider context (O'Grady and Jadad, 2010).

While shared decision-making refers to the two-way knowledge exchange relevant to the decision at hand, collaboration broadens the perspective and allows for more participants, such as supporters or assistants, varying from family members to public advocates. Also, collaboration is not focused on decision-making as an event, but as a process of constructing a care plan. A further effect of

collaboration might be that the problem to be decided on is reframed/rephrased during the decision-making process. Finally, collaboration is essential in the care process, even in the most mundane elements of caregiving, such as feeding, washing, and dressing of dementia patients in a nursing home. Here the values of responsibility and responsiveness advocated by the ethics of care fully apply (Tronto, 1993).

A truly collaborative approach to decision-making underscores the relevance of a wider, non-medical context of patient values and preferences. Assisting patients to elaborate on their wishes and on what they consider of relevance in their life can be seen as an enabling approach to decision-making. Thus, one seeks to compensate for limitations in cognitive abilities and communication by addressing individual strengths. For example, patients with dementia are often quite capable of communicating what they value, and their capacity to understand can also be far greater when the focus is on experiences, values, and feelings, rather than on recollection and the rational handling of information. By proceeding in such a way, collaboration in decision-making can promote patient's self-esteem and identity (Hellstrom *et al.*, 2007; De Boer *et al.*, 2012). Similarly, it has been shown that while some patients with psychosis have very limited insight into or refuse to acknowledge their diagnosis, they may be prepared to accept that they need treatment and understand the side effects of medication (Aydin *et al.*, 2013).

### Current statutory support for supported decision-making

Even in the absence of formal laws that codify supported decision-making, several jurisdictions mandate, sometimes via policy, consultation with the person with the disability once a substitute decision maker has been appointed. For example, in Australia, under the NSW Guardianship Act 1987, Section 4 Principles, it is the duty of a substitute decision maker exercising functions under the Act to (i) take the views of the person in relation to whom they are exercising the function into account when making a decision on their behalf; (ii) restrict the freedom of decision of the person as little as possible; and (iii) encourage, as far as possible, the person to be self-reliant in matters relating to their personal, domestic, and financial affairs.

The same is true in the Netherlands under the Medical Treatment Contract Act (MTCA, 1995). The surrogate decision maker is obligated to involve the incompetent patient as much as possible in the decision at hand. However, how this should be done

remains largely unclear, while on the other hand the physician holds the responsibility to watch over the surrogate to see whether he executes his role properly as "a good representative."

English case law stipulates a similar approach (e.g., in the case of *Bailey v Warren* (2006)), while the Mental Capacity Act (MCA, 2005a) prescribes steps to support individuals with DMD in the decision-making process in order for them to participate maximally. Specifically, relating to the determination of the best interest of individuals lacking capacity, Section 4(4) of the MCA prescribes that the person making the determination should "as far as reasonably practicable, permit and encourage the relevant individual to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him."

Specific legislative authority for supported decision-making has been also available in Alberta, Canada since 2009. A person with DMD in personal decision-making, but with capacity to appoint a "supporter," can appoint one or two "supporter/s" to assist them when making personal decisions. Support is provided by assisting with information collection, decision-making, and communicating the decision, but not making the decision on behalf of the person (Alberta Human Services, 2013). Similarly, in Yukon, supported decision-making agreements in regards to both personal and financial decisions have been available since 2005 (Yukon Health and Social Services, 2013).

### Who should act as "supporter" and how should they be appointed?

A range of supporters or assistants have been proposed – from the obvious family members to volunteers and public advocates as well as those who have interests in the individual's care. Further, there has been some variation in the nature of the appointments of the supporter. While most existing models rely on self-appointment of assistants, there have been proposals in some jurisdictions to externally appoint the assistant, particularly if the person lacks capacity to make the appointment.

Dutch law further distinguishes a so-called "unappointed surrogate": If there is no self-appointed surrogate decision maker and an externally appointed decision maker (external meaning appointed by the court) is not available, the MTCA stipulates who might act as a surrogate decision maker (mostly family or next of kin).

It is important to note that the capacity to appoint a supporter or assistant decision maker must be distinguished from the capacity to make

decisions in the domain to be assisted (e.g., personal, health, or financial decisions). Usually, but not always, the capacity task for appointing an assistant would be less complex than making the broader decisions (Kim and Appelbaum, 2006). However, this may not be the case if the person has a complex or conflictual social or family environment where the choice of who to choose and trust may indeed be complex.

### **A stepwise and practical approach to a collaborative model of supported decision-making**

From the foregoing discussion we may conclude that there is ample statutory support for supported decision-making, but also that the question of “who” should act as a supporter is better addressed than the question of “how” support in decision-making can be given.

#### **Aids to maximize participation in decision-making**

An important step in the process of supporting those with DMD is the provision of aids to maximize participation in decision-making. At a simple and general level this can range from attending to barriers to communication such as background noise, poor lighting, flat hearing-aid batteries, addressing literacy or language difficulties, tailoring and personalizing information, giving sufficient time for assimilation of information, and using accessible visual aids, to establishing rapport, creating a safe context, and establishing a relationship of trust and empathy (Parker and Cartwright, 2005). At a more specific level, participation can be enhanced by buttressing cognitive deficits, which might otherwise interfere with decision-making. A useful starting point in doing so is understanding the cognitive skills required for decision-making using the operationalized definition of capacity, viz.:

1. Ability to understand and retain relevant information.
2. Ability to appreciate the situation and its likely consequence.
3. Ability to manipulate information rationally (or reason about it) in a manner that allows one to make comparisons and weigh options.
4. Ability to communicate a choice.

If we look at each of these elements, we find areas that have been targeted to aid decision-making. First, the ability of people with impaired capacity to understand information relevant to their decision-making can be enhanced in order to support their

decision-making. In fact, regardless of whether a person has a DMD or not, the presentation of the information about the health problems, treatments, and choices available to the patient, i.e., “the education step” (Darzins *et al.*, 2000) is the first essential step in decision-making. This concept is well set out in the guidance provided by the MCA Code of Practice in England and Wales on “how to support people to make decisions for themselves, or play as big a role as possible in decision-making” (Mental Capacity Act, 2005b).

Second, in patients with a range of mental and neurological disorders, interventions aimed at maximizing *understanding* and *appreciation* by supporting cognitive functions, such as memory, may help to optimize capacity. Such efforts can be fruitful even in patients who might otherwise be deemed as lacking capacity. Simplified explanations, repetition, and recognition cueing have increased patient understanding of treatment regimens in patients with schizophrenia, dementia, and multiple sclerosis (Dunn & Jeste, 2001; Combs *et al.*, 2005; Moye *et al.*, 2006; Palmer & Jeste, 2006; Basso *et al.*, 2010).

The next focus of supported decision-making is providing assistance with the rational manipulation of information, considering the options available and the consequences of choosing each option (Victorian Law Reform Commission, 2012). Frequently, the deficit in patients with DMD is frontal or executive dysfunction, or more specifically, deficits in abstract thought, the holding of various options in one’s mind simultaneously and projecting possible outcomes. Providing frontal or executive dysfunction buttresses or scaffolding, using problem solving strategies, and making outcomes concrete and explicit in a way accessible to the person, can be helpful in this context (e.g., Rubright *et al.*, 2010; Hamann *et al.*, 2011). Another aid to decision-making might be obtaining information from written documents or family members about the person’s former preferences, values, and beliefs, which might be otherwise inaccessible to the person due to frontal lobe or autobiographical memory deficits (Hertogh, 2009).

Finally, there may be a need to assist the person in communicating their wishes and decisions to others and to advocate for the implementation of their decisions, or to take action to ensure that their decisions are respected and implemented (Victorian Law Reform Commission, 2012).

#### **A practical model**

Under the acronym ASK ME, we recommend the following steps for a model of supported

decision-making that uses collaborative principles and builds on a positive, relational concept of autonomy:

**Step 1. ASSESS** where the person's strengths and deficits lie, whether it be in holding information in working memory, weighing alternatives, projecting and planning with consequences, or communicating. Having a supportive and flexible carer might be a strength. Knowing where a person's strengths and weaknesses lie helps to determine exactly how best to simplify/limit the task and maximize the ability to understand.

**Step 2. SIMPLIFY** the task. Limit the capacity task to the specific decision at hand and do not overstate the decision. People are more likely to retain or participate in decision-making for a simple, restricted decision than a large, global decision. For example, is the decision merely to give information to an aged care team to organize care rather than understand the need for care? Is it to express wishes regarding desire for pain relief and comfort (i.e., participating in advance care planning) rather than making an actual advance care directive? It is also important to pitch the information provided at the individual's level of understanding, i.e., avoid medical jargon and use straightforward sentences where possible.

**Step 3. KNOW** the person. To find a common ground for working together, it is essential to find out what they consider of relevance in their life, what their long held values are, and whether they still affirm these values. Where possible, gain information about and understanding of their values and/or past patterns of decision-making. Information about past allegiances and trust might be evident in documents such as powers of attorney or wills. This is particularly crucial if the person has a degenerative disease and had decisional capacity previously. In order to find a common ground, it is essential to understand what is important and meaningful to the person in their life right now as it pertains (in any way) to the decision at hand (e.g., in a decision to decide about residential aged care, the person may be more interested in food or family than accommodation specifically). Respect the person's precedent autonomy where possible, but also, where appropriate, respect their right to change their mind (Jaworska, 1999; Hertogh, 2011).

**Step 4. MAXIMIZE** the ability to understand. Attend to and remedy all hindering factors to communication. Give time, optimize the environment, simplify and concretize information, and provide it in an accessible format, e.g., visual aids if necessary. It is conceivable and probably more practical for visual aids to encompass more than just written information, as written information is often complex, difficult to read, and written in a way that decreases

understanding especially in people with a cognitive and/or sensory deficit. Use of simple pictorial representations of the choices or simple linear representations of the choices to be made would enhance the contribution of the person making the decision. Where possible, approach the individual at a time when they are optimal in their cognition, e.g., first thing in the morning or after a course of treatment such as dialysis or blood transfusion.

**Step 5. ENABLE**, based on the (results of the) former steps, participation in decision-making by tailoring the degree of support to the complexity of the decision and the seriousness of the consequences of the decision. Assist and facilitate the communication and implementation of the decision.

Importantly, the ASK ME approach to supported decision-making is not restricted to healthcare. Similar principles apply in relation to decision-making in legal settings as expressed in the relationship between the legal professional and their client, and in financial settings in the relationship between the accountant or financial advisor/planner and their client. Further, as said, the essence of collaboration is to find a common ground for working together while understanding the person, their strengths, and weaknesses. As a consequence of this principle, the effect of the ASK ME approach might be that the problem to be decided on is rephrased or reframed during the process or a person is reminded of or cued about previous decisions. Another effect might be a true medico-legal or medico-financial collaboration where healthcare professionals assist other professionals in the understanding of the person.

### Risks, problems, and limitations

There are a range of problems and risks related to supported decision-making. An important practical impediment is the time constraint faced by practitioners in their busy clinical settings. Also, the model proposed here would be impractical when the patient is in an emergency and in need of immediate treatment. Further, this approach to decision-making calls for an active role of health professionals and high quality communicative skills. Collaboration asks for attentive listening, responsivity, and other competencies, for otherwise patients will easily be overruled. It demands true willingness and preparedness to see the patient as a partner in the decision-making process, and to encourage and preserve patient ownership of decisions as much as possible.

Among the hazards we must mention the risk of overestimating a person's capacity. Specifically in the context of impaired executive function, patients

may be substantially controlled by verbal and behavioral cues and clinicians can thus easily induce acceptance of a care plan or other decision (Workman *et al.*, 2000). This places a huge responsibility on the shoulders of healthcare professionals and calls for a scrupulous, preferably multidisciplinary, team approach in which clinical, neuro-psychological, and ethical competencies are combined. Patients, or those supporting them, may be vulnerable to the influence or skewed perceptions of those who seek to gain from the decision at hand. Indeed, there may be certain complex situations which preclude supported decision-making. For example, adopting a truly non-partisan approach may be difficult in the face of family conflict when choosing to appoint or benefit a family member over others is the decision at stake.

The reverse dilemma, namely of *underestimating* a person's capacity, can arise in relation to Advance Directives/Decisions where the question is raised how to accommodate for the problem of preference adaptation in view of a former advance treatment refusal. Indeed, as stated above, people have "a right to change their mind, even when their minds have changed" as a consequence of a neurodegenerative disease. Generally speaking however, the dilemma remains on how to judge the authenticity of such changes. The Dutch MTCA as well as the English and Welsh MCA hold that Advance Directives/Decisions to Refuse Treatment, when valid and applicable to the current circumstances, must be followed. Both statutes however make allowance for instances in future when the healthcare professional might have justified reasons not to follow the dictates of the Advance Directives/Decision, thereby acknowledging that our lived reality is much more complex than the simplicity of written Advance Directives/Decisions. In essence, it is not always possible to make all-inclusive decisions about the future based on current experiences (Hertogh, 2011). Indeed, it must be recognized that there is no easy way out of the dilemma generated by the conflict between past and present wishes. Nonetheless, as far as our efforts are directed toward equal recognition for people with DMD by affording them optimal agency in supportive decision-making, it is our position that we prefer to "err on the side of life" in case of a discrepancy between a current patient's preference and his former Treatment Refusal.

In conclusion, by and large the supported decision-making concept requires the healthcare (or legal and financial) professional to involve patients as much as possible in decisions relating to their care and treatment/welfare regardless of their areas of deficit. This concept is supported by several jurisdictions around the world. Although there are numerous limitations to this concept and its applic-

ability, some of which are enumerated above, we consider the supported decision-making concept to be the best way forward in maximizing autonomy for patients with dementia and other capacity-limiting disorders and recommend the ASK ME approach. For as one of them, Cary Henderson (1998, p. 7), denotes in his autobiography: "Damn it we're people too! And we want to be talked to and respected as if we were honest to God real people."

We recommend greater utilization of this concept in the global context.

### Conflict of interest

None.

CARMELLE PEISAH,<sup>1,2</sup> OLUWATOYIN A. SORINMADE,<sup>3</sup> LEANDER MITCHELL<sup>4</sup> AND CEES M.P.M. HERTOGH<sup>5</sup>, on behalf of the International Psychogeriatric Association Taskforce on Capacity

<sup>1</sup>School of Psychiatry, University of New South Wales, Sydney, Australia

<sup>2</sup>Australian Centre for Capacity, Ethics and the Prevention of Abuse of People with a Disability (ACEPPD), Sydney, Australia

<sup>3</sup>Older Adult Psychiatry Directorate, Oxleas NHS Foundation Trust, London, UK

<sup>4</sup>School of Psychology, Ageing Mind Initiative, University of Queensland, Brisbane, Australia

<sup>5</sup>Department of General Practice & Elderly Care Medicine, EMGO Institute for Health and Care Research, VU University Medical Center Amsterdam, Amsterdam, The Netherlands

Email: cmpm.hertogh@vumc.nl

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