

# Capacity to Participate in Everyday Decisions in People Living with Dementia

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None

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**About this paper:** This student essay, by a 1<sup>st</sup> year medical student, won the Dr Jim Appleyard Prize for Reflection on Practice, for best essay on person-centred care.

**Introduction:** There are an estimated 50 million people worldwide living with dementia (World Health Organisation, 2019). Through natural disease progression, cognition in a person living with dementia (PWD) deteriorates, potentially leading to inability to perform everyday tasks. A PWD can become a risk to themselves and be deemed to “lack capacity”.

Capacity refers to an individual’s ability to make particular decisions. The legal frameworks relating to capacity are set out within the *Mental Capacity Act 2005*.

During my time working in a care home dementia community, I have witnessed that once an individual has

been assessed as lacking capacity in a particular domain, services generally fail to re-evaluate capacity in each daily decision. The main examples of this are in activities of daily living (ADLs), like the choice of a shower or what meal to eat. The result is that the PWD loses a degree of autonomy, as decisions are assumptively made for them based on pre-established levels of capacity.

This has led me to reflect that a basic decision most people make each day, such as choosing a meal, is perhaps a taken for granted concept when thinking from a PWD's perspective. While PWDs may have impaired cognition, it is easy to imagine how frustrating this may be, particularly if you face communication barriers. It could lead to feelings of imprisonment and suppression in a world where nobody listens or takes your decision into account: a world that for PWDs, may already seem unfamiliar enough.

My experiences in this clinical environment disregard two fundamental aspects of the *Mental Capacity Act 2005*: capacity fluctuates,

and capacity is specific to each decision. Caregivers must look past a person's dementia diagnosis, ensuring capacity is continuously reconsidered and evaluated at the time of each decision. While major decisions (such as moving into care) may define a living environment, it is ADLs that determine how an individual actually experiences their life, and through this lens, it can massively impact quality of life (QOL).

This review delves further into capacity and decision making in those living with dementia, specifically their day-to-day decisions, and aims to identify whether my observations in practice are widespread.

### **Literature Review:**

**Legal and Ethical Principles:** The *Mental Capacity Act 2005* is an Act of Parliament designed to protect and empower those lacking mental capacity, supporting them to make their own decisions. There are five principles (Fig. 1).

A person must be assumed to have capacity unless it is established that he lacks capacity.

A person is not to be treated as unable to make a decision unless all practicable steps to help him do so have been taken without success.

A person is not to be treated as unable to make a decision merely because he makes an unwise decision.

An act done, or decision made, under this Act or on behalf of a person who lacks capacity must be done, or made, in his best interests.

Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

Figure 1: The 5 principles of the *Mental Capacity Act 2005*

A central feature of the *Mental Capacity Act 2005* is that someone may have capacity for some decisions but not others, or their capacity may fluctuate. However, this criterion is perhaps one of the most difficult to enforce. The Act discusses optimising the conditions (time and place) to enable individuals to participate as much as possible in their decisions,

but is this practical in real-life situations? From my observations, caregivers simply do not have enough time to assess every decision that PWDs must make as the *Mental Capacity Act 2005* suggests. Furthermore, many ADL decisions occur in the early morning/late evening, which is when PWDs tend to be most confused. If caregivers were to discuss decisions at a separate time when the individual is more lucid, then a more personalised decision may be made, but the same issue arises that capacity is not assessed at the specific time of decision making, forming an endless cycle in which the aims of the *Mental Capacity Act 2005* are not achieved.

While the *Mental Capacity Act 2005* provides a fundamental framework to support those lacking capacity, I have noticed that it isn't always entirely effective. This is reflected by the CQC and House of Lords Select Committee, who identified serious issues with practical implementation of the *Mental Capacity Act 2005*, leading the Department of Health to commission a National Institute for Health and Care Excellence (NICE) guideline for

decision making and mental capacity (NICE, 2020). These guidelines place emphasis on empowering people with difficulties making independent decisions and give detailed recommendations on supporting decision making. NICE provides specific guidance on daily decisions, stating that the nature of assessment in everyday decisions should be proportionate to the complexity and significance of the decision itself. With regard to the best interest principles of the *Mental Capacity Act 2005*, NICE recommends a less formalised approach for day-to-day decisions, with recurring decisions being reported in care plans with routine timescale reviews. This allows caregivers to closely reflect the needs and choices of each individual in a more timely and reasonable manner.

The General Medical Council (GMC) also disseminates guidance for doctors around mental capacity, with tools to assist assessment, and advice to support decision making (General Medical Council, 2020). The GMC has formulated their own seven principles of mental capacity, which apply specifically to the practice of doctors.

### ***Mental Capacity Act 2005 in***

**Practice:** Many organisations explain how capacity should be handled in practice, but it is difficult to evaluate the efficacy of the *Mental Capacity Act 2005* in real situations. This review explores articles published after its implementation in 2007 and seeks to learn how daily decisions are made in practice, determine levels of participation from PWDs, and the benefits of participation.

### **How are daily decisions made and how do PWDs participate?**

A 2018 systematic review explored how PWDs are included in day-to-day decisions about their care (Daly, Bunn and Goodman, 2018). The review mentions that where PWDs lived in care settings, mental capacity assessments were in place, but evidence suggested staff often made day-to-day decisions on behalf of PWDs without reassessment, much as I have seen in practice.

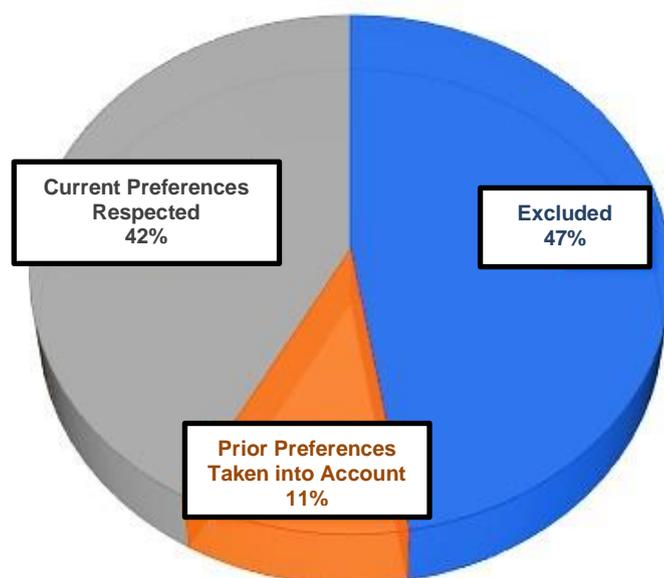
Another study analysed interviews, and observed care to categorise levels of participation in decision making of PWDs and caregivers (Smebye, Kirkevold and Engedal, 2012). Five

categories were identified: autonomous, delegated, shared, pseudo-autonomous (assumed) and non-involvement, with shared being the most common. However, clear differences were noted between opinions of some PWDs and their caregivers, with carers often believing the PWD was less involved than the PWD did, and PWDs believing communication regarding daily decisions was poorer than caregivers thought. This correlates with one of the introductory statements from Daly, Bunn and Goodman (2018, p. 7), that 'people have the desire and ability to participate in decision making about everyday care but are regularly underestimated by staff and family care partners.' So, while shared decision making was supposedly the commonest level of participation, there was little evidence of mental capacity being systematically tested within the study from Smebye, Kirkevold and Engedal (2012), which was troubling as PWDs expressed that involvement in decisions was far more important than actual outcomes.

Other articles used different categories to indicate how decisions are made for those with dementia. Three themes for

degree of participation were identified within a review relating to care services (Fig. 2) (Taghizadeh Larsson and Österholm, 2014). Nine cases were categorised as excluded from decisions, with many families expressing this was the only way to ensure safety and wellbeing of PWDs. Two cases showed involvement of delegated individuals or advanced planning documents, which allowed consideration of prior preferences. The remaining eight, many in earlier stages of dementia, had current preferences respected. This seems to demonstrate

### CATEGORIES OF PARTICIPATION



*Figure 2: Pie Chart showing levels of participation in decision making in those with dementia. Data gathered from Taghizadeh, Larsson and Österholm (2014). Excluded category comprises greatest proportion.*

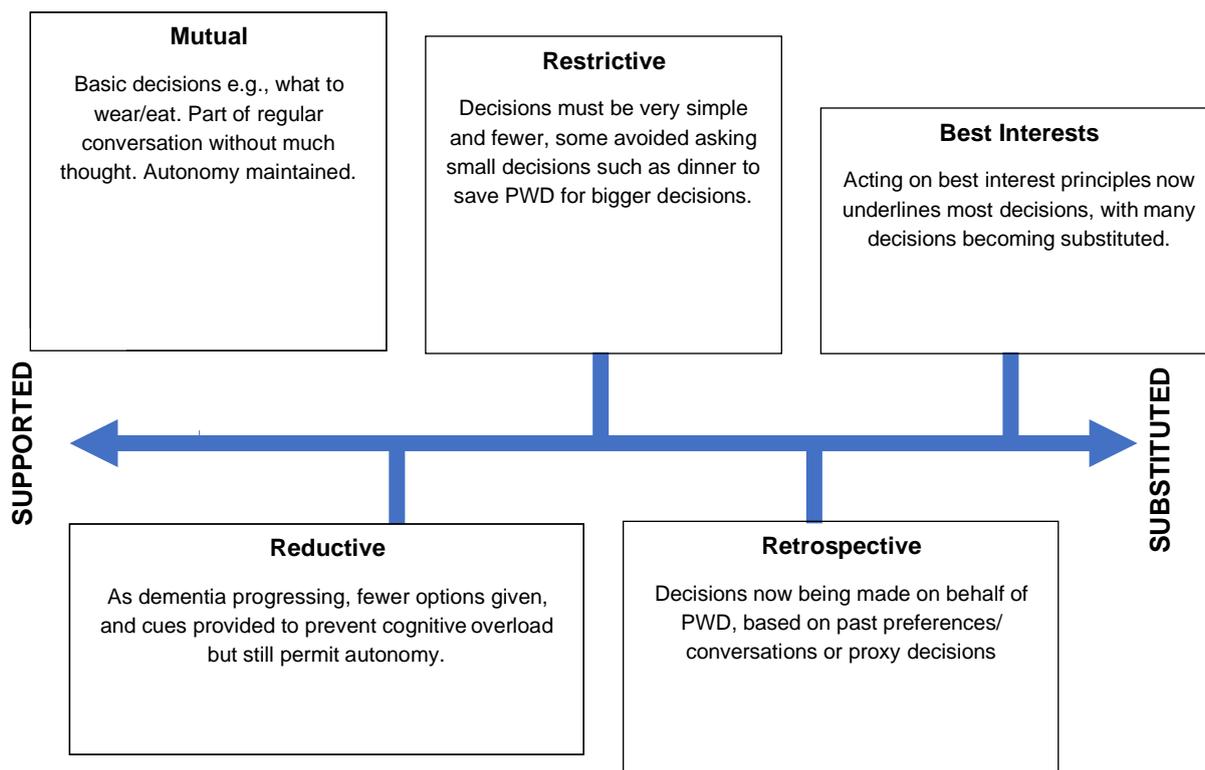


Figure 3: Five salient categories identified in continuum of decision-making participation, ranging from low level support to full substitution. Important to note that movement through continuum is non-linear with some dyads starting and finishing at different points for different decisions.

that caregivers frequently make assumptions, and a greater proportion of decisions are made without PWDs participating. Once again, this correlates with my clinical observations that regardless of legal frameworks, implementation of the *Mental Capacity Act 2005* is still complex.

In a separate study, twelve dyads (PWD and family caregiver) were interviewed to investigate how everyday decisions occur (Samsi and

Manthorpe, 2013). A continuum was constructed representing the discourse of decision making, displayed in Figure 3. There was evolution from mild support in joint decisions to completely substituted decisions representing PWD non-involvement. In early dementia, cues and restriction of choices help to maintain autonomy, but through disease progression, decisions start to be made on behalf of PWDs using best interest principles and prior preferences.

This continuum is valuable in demonstrating that even in supported decisions, it is very simple for caregivers to manipulate PWD's choices by reducing or restricting options. As I have seen in care settings, time constraints and de-personalisation can present challenges to continuous re-evaluation of capacity, making it too easy to move quickly along the continuum and revert to prior decisions and best interests, hence diminishing the autonomy of PWDs.

**Benefits of greater participation in decision making:** Many of these research articles conclude by emphasising the importance of decision making in person-centred dementia care. Evidence from Daly, Bunn and Goodman (2018) suggests that PWDs want to participate, and their review found that involvement in daily decisions correlated with heightened self-esteem, sense of purpose and self-worth, reduced depressive symptoms and overall greater QOL, perhaps more so than noteworthy decisions such as treatments or relocations. This is echoed by Smebye, Kirkevold and

Engedal (2012), who discuss that optimising potential for decision making contributes to wellbeing and QOL, and using remaining cognitive abilities prevents excess disability. They also state that exclusion from decisions can result in depression and frustration, which epitomises what I have seen in my clinical experiences.

Correlations between involvement and wellbeing are supported by a review which directly determined the relationship between decision-making involvement (DMI) and QOL for 217 PWDs in care homes (Menne *et al.*, 2008). Their DMI scale ranked fifteen dimensions of daily decisions on a 4-point scale, 0 meaning non-involvement and 3 being very involved. This scale was then related to wellbeing through a self-reported QOL in Alzheimer's Disease (QOL-AD) (Thorgrimsen *et al.*, 2003) scale using Pearson correlations. DMI ratings and QOL were significantly correlated, suggesting PWDs who reported greater participation in decision making also had better QOL.

Many of the authors stress that engagement in daily decisions plays a

vital role in maintaining a sense of identity and QOL, but this can be a grey area in dementia due to conflict between maintaining autonomy while ensuring health is not compromised. One phenomenological study interviewed PWDs to directly address why involvement in decision making is so important to them (Fetherstonhaugh, Tarzia and Nay, 2013). In detailed interviews, PWDs raised some fundamental points. The importance of subtle support rather than taking over was highlighted. The interviewees wanted their caregivers to suggest ideas and formulate strategies which enable them to maintain independence. This was seen to be empowering and reduced frustration by giving the person a sense of purpose. Again, this is something demonstrated in my clinical experience, as those who are often non-compliant in relation to ADLs, such as having a shower, can show completely different attitudes when given responsibilities, such as looking after a baby in doll therapy. The PWDs interviewed wanted to maintain their independence and to feel central to their decisions, as exclusion led to resentment and feelings of

insignificance. These interviews give valuable insight into the essence of decision making and an apt quote by one member of the study showed the importance of *feeling like I am still here*.

**Conclusion:** This literature review recognised numerous barriers to participation. One article suggested that caregivers lack time and resources to adequately assess capacity to fully involve those they care for (Daly, Bunn and Goodman, 2018). There are lots of clinically applicable tools for assessing cognition (e.g. Mini Mental State Exam (MMSE)), but no instrument to reliably assess capacity for ADLs (Lai and Karlawish, 2007). NICE guidelines make the *Mental Capacity Act 2005* more accessible to care services, but still fail to suitably equip those providing care with the means to improve their skills. The GMC's guidelines apply specifically to the practice of doctors, who are not as intimately involved in the daily lives of PWDs compared to primary caregivers. Overall, guidance available in care settings appears inadequate.

There is also insufficient research into daily decisions in care settings, where the routine of task-oriented care is a significant, consistent inhibitor associated with reduced opportunity for choice (Daly, Bunn and Goodman, 2018). This is reiterated by Smebye, Kirkevold and Engedal (2012) who say it is difficult to implement the ideologies of the *Mental Capacity Act 2005* as institutional objectives are prioritised over individuals' needs. My personal experience of research highlights that daily decision making in dementia care is probably an overlooked area, with the bulk of research exploring driving, treatments, relocations etc., rather than "small acts of care", which are omnipresent decisions likely to form the majority of discourse between PWDs and caregivers (Samsi and Manthorpe, 2013).

In order to bypass these barriers in future practice, carers need more time if they are to repeatedly reassess capacity at the time of each decision. Further research must be completed to bring awareness to this underestimated area of capacity and resolve the systemic issues

responsible for non-involvement of PWDs. Going forward, focus must be on disseminating accessible guidance, tools and training to empower caregivers to involve PWDs in their lives and permit greater use of remaining abilities that are correlated with better wellbeing.

The growing population living with cognitive impairment accentuates the importance of appropriately assessing capacity for ADLs. Reflecting on my personal observations, this review has indicated that there is a pattern of often poorer participation in decision making for PWDs across care facilities and the aims of the *Mental Capacity Act 2005* to empower individuals are not yet realised. The importance of autonomy to PWDs is something I am sure to carry into my work environment and future practice.

In conclusion, people should not be defined by dementia, and it is vital to remember this powerful quote: 'My name is not dementia' (Alzheimer's Society, 2010, p. 1).

## References:

- Alzheimer's Society (2010) 'My name is not dementia; Literature review', (April), p. 64.
- Daly, R. L., Bunn, F. and Goodman, C. (2018) 'Shared decision-making for people living with dementia in extended care settings: A systematic review', *BMJ Open*, 8(6), pp. 1–11. doi: 10.1136/bmjopen-2017-018977.
- Fetherstonhaugh, D., Tarzia, L. and Nay, R. (2013) 'Being central to decision making means I am still here!: The essence of decision making for people with dementia', *Journal of Aging Studies*, 27(2), pp. 143–150. doi: 10.1016/j.jaging.2012.12.007.
- General Medical Council (GMC) (2020) 'Decision making and consent', *Ethical guidance for doctors*. Available at: <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/decision-making-and-consent>.
- Lai, J. M. and Karlawish, J. (2007) 'Assessing the capacity to make everyday decisions: A guide for clinicians and an agenda for future research', *American Journal of Geriatric Psychiatry*, 15(2), pp. 101–111. doi: 10.1097/01.JGP.0000239246.10056.2e.
- Menne, H. L., Tucke, S. S., Whitlatch, C. J. and Feinberg, L. F. (2008) 'Decision-Making Involvement Scale Family Caregivers', *American Journal of Alzheimer's Disease & Other Dementias*, 23(1), pp. 23–29.
- Mental Capacity Act 2005*, c. 9. Available at: <https://www.legislation.gov.uk/ukpga/2005/9> (Accessed: 17 April 2021).
- National Institute for Health and Care Excellence (NICE) (2020) *Decision-making and mental capacity*. NICE Guideline [NG108]. doi: <https://www.nice.org.uk/guidance/ng108>.
- Samsi, K. and Manthorpe, J. (2013) 'Everyday decision-making in dementia: Findings from a longitudinal interview study of people with dementia and family carers', *International Psychogeriatrics*, 25(6), pp. 949–961. doi: 10.1017/S1041610213000306.
- Smebye, K. L., Kirkevold, M. and Engedal, K. (2012) 'How do persons with dementia participate in decision making related to health and daily care? A multi-case study', *BMC Health Services Research*, 12(1), pp. 1–12. doi: 10.1186/1472-6963-12-241.
- Taghizadeh Larsson, A. and Österholm, J. H. (2014) 'How are decisions on care services for people with dementia made and experienced? A systematic review and qualitative synthesis of recent empirical findings', *International Psychogeriatrics*, 26(11), pp. 1849–1862. doi: 10.1017/S104161021400132X.
- Thorgrimsen, L., Selwood, A., Spector, A., Royan, L., de Madariaga, L.M., Woods, R.T. and Orrell, M. (2003)

Whose quality of life is it anyway? The validity and reliability of the quality of life-Alzheimer's disease (QoL-AD) scale. *Alzheimer Dis Assoc Disord.* 17(4), pp. 201–8.

World Health Organisation (WHO) (2019) *No Title, Dementia Factfile*. Available at: <https://www.who.int/features/factfiles/dementia/en/> (Accessed: 06 March 2021).