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Title

Capacity and decision making in dementia care

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Abstract

As the prevalence of dementia continues to rise globally, ensuring that individuals living with the condition are supported in making decisions about their lives is increasingly important. This article explores the legal, ethical, and practical dimensions of decision-making capacity in dementia, with a focus on the application of the Mental Capacity Act 2005 in England and Wales. It outlines the principles and processes for assessing capacity, making best interest decisions, and the role of legal instruments such as Lasting Powers of Attorney and Deprivation of Liberty Safeguards. The discussion highlights the importance of shared decision-making and the need for community nurses to actively involve family carers and individuals with dementia in conversations about their care and future. Two fictionalised case studies illustrate the complexities of real-life decision-making scenarios, offering insights into how legal frameworks and person-centred approaches can be integrated in practice. The article also considers the potential of decision aids to enhance autonomy and participation for people with dementia. This paper aims to support community nurses in delivering compassionate, lawful, and inclusive care.

Introduction

The prevalence of dementia is increasing worldwide, and in the UK, it is estimated that currently there are over 950,000 people living with the condition and expected to rise to nearly 2 million by 2050 (Wittenberg et al. 2019). Dementia is an umbrella term describing a range of symptoms characterised by impaired cognitive and social functioning and behavioural changes (Barber 2020). There are over 200 causes of dementia, with the most common being Alzheimer's disease, vascular, Lewy body, mixed and frontotemporal (Prince et al. 2014). Dementia is most common in those over the age of 65, but it can also occur in younger people, termed Young Onset Dementia (Knight and Pepper 2024).

Decision-making is essential for maintaining autonomy, allowing for control over the personal, social, professional and legal aspects of a person's life (Bhatt et al. 2020). As dementia is a progressive disease, its impact on cognitive functioning increasingly affects the person's ability to make decisions (Davis et al. 2017). However, impaired cognition is not always the reason for a person with dementia to struggle to assert control over their life, as societal factors such as being excluded from or ignored during decision-making conversations may also have an impact (Bhatt et al. 2020). This is often because people in a caring role (both formal and informal) underestimate the person with dementia's ability and inclination to contribute to discussions (Daly et al. 2018). Deliberate effort on the part of community nurses and other health and care professionals is therefore needed to ensure decision making is a shared and supportive process (Mattos et al. 2023), and any discussions should not automatically minimise the contribution from the person with dementia (Miller et al. 2016).

Where life-changing topics are being discussed, such as decisions on medical care or financial management, legal frameworks are in place to support decision-making. These frameworks exist to protect the interests of the person with dementia and allow for a range of involvement of the individual with whom the decision is being made, from active participation through to advocacy.

Legal context

In English Law, individual autonomy and decision-making are protected by various statutes and common law. The primary legal frameworks include the Mental Capacity Act (MCA) (2005) from which we derive the MCA Code of Practice (2007), the Deprivation of Liberty

Safeguards (DoLS) (2009) and the DoLS Code of Practice (2009). It is important that community nurses, as with all health and care professionals, understand the legal parameters of this legislation and apply the proper principles and tests to support people with dementia in their care to make their own decisions, and where unable due to a lack of capacity, to support 'best interests' decision making.

At the outset for every assessment of a person's capacity, there are five key principles that must be applied to every individual for whom a decision may need to be made (see box 1) (MCA, 2006).

Box 1 approximately here

Practical examples and details about how the Act must be applied and when someone else may make decisions for a person assessed as lacking mental capacity can be found in the MCA code of practice (2007).

Establishing Mental Capacity

We must always start from the presumption that everyone has the capacity to make their own decisions, unless proved otherwise, and this is a key principle of the MCA. It is for health or care professionals (or the person needing a decision to be made) to decide whether someone with dementia has lost capacity to make that specific decision. So how do we establish when someone lacks capacity? The MCA S2(1) provides a definition:

> *… a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain MCA 2005; S2(1).*

In assessing a person's capacity, three questions are asked to determine whether a person can make a decision about a specific matter, at a specific time:

1. Can they make the decision about the specific matter?
   This is about their ability to decide. If they cannot, then the following two questions should be asked:
2. Does the person have an impairment or disturbance in the functioning of the person's mind or brain?
   The answer to this if someone has a diagnosis of dementia is 'yes'; so
3. Does that diagnosis affect their ability to make the specific decision in question?

In determining a person's capacity to make a decision, the following considerations need to be made (MCA 2005) (guidance and further discussion can be found in S3 of the MCA Code of practice):

The person must be able to:

1. understand the information relevant to the specific decision,
2. retain that information,
3. use or weigh up that information as part of their decision-making process, and then
4. communicate their decision.

Capacity can fluctuate. Because capacity is both time and decision specific, someone capable of making a decision about one matter might not have capacity to make a decision about another. Someone may be capable of making a certain decision at breakfast time but lack capacity to make that same decision later in the day. Timing a capacity assessment to try and give the person the best chance of having capacity to make their own decision is vital, although not always possible in an emergency.

It can sometimes be difficult to establish exactly what the ‘relevant information’ comprises. It is not necessary to explain everything about the matter to the person, but enough information should be given to enable the person to understand the essential aspects of the matter. For medical treatment, for example, this might include the nature of the treatment, purpose and necessity for the treatment, risks and benefits and the consequences of receiving or not receiving the treatment. The relevant information given should typically include information about the reasonably foreseeable consequences of making one decision over another or not making a decision at all. The person being assessed does not need to demonstrate an understanding of all the information, just the ‘salient factors’.

All possible efforts to explain the relevant information must be taken. This requires tailoring communication to the person’s needs, and especially important in dementia – for example, key information could be given in writing, in bullet points, or by using visual aids, such as Talking Mats™. Consider the language used, or how information is presented and communicated (Pepper and Harrison Dening 2023).

The person needs to be able to retain the relevant information for long enough to weigh it up and make the decision. It does not matter that they cannot retain the information after the decision is made. The assessor must record the steps taken to assess capacity, the decision taken, and the reasons why that decision was reached.

Best Interest Decisions

If it is determined that the person lacks mental capacity to decide about the matter, the next step is to make a best interest decision to decide on the action to be taken for the person. ‘Best interests’ is not defined in the MCA, but S4 MCA sets out a checklist to follow to ascertain best interests. Principally, the person must be supported and encouraged, as far as reasonably practicable, to make their own decisions.

The basis of any best interest decision must be guided by making decisions that the person may have made for themselves if they had capacity, and not the decision others would make in that situation. Best interests should be determined by considering all the relevant factors and circumstances, such as the person’s values and beliefs, any previously expressed wishes, (any that have been previously documented) and not just those that the decision maker thinks are important. Importantly, might the person regain capacity at some point in the future, an example might be, are you requiring a decision when the person has an infection where once treated, they may then be able to make the decision.

In best interest processes, the decision maker should consult and consider the views of others (where practicable and appropriate (S4 (6), MCA). This may include anyone named by the person as someone to be consulted on such matters in question, anyone caring or interested in their welfare, an attorney named in the person’s LPA who does not have authority to make the decision in question or any court appointed deputy for the person. Although not a requirement in the MCA, it is good practice to hold a meeting of all interested parties. In health and social care settings, multi-disciplinary’ meetings, can be arranged by anyone who needs to make a best interest decision and are particularly helpful in complex matters or where there is a dispute over what is in a person’s best interest with a record kept detailing how decisions were reached.

Case studies

We now present two fictionalised case studies to illustrate some of the issues relating to supporting decision making for people with dementia and their family carers. Reviewing case studies offers ideas on how community nurses can improve both their clinical practice and so patient outcomes. They can also generate a deeper and multi-faceted understanding of complexities encountered in a real-life clinical context (Seshan et al., 2021). Community nurses and nursing students exposed to such teaching approaches usually become more resourceful in integrating theory with practice (Savery 2019).

Case study 1

> Ben was diagnosed with young onset Alzheimer's disease by the team at his local memory assessment service. He had experienced changes over the previous 18 months that eventually led him, with the encouragement of his wife Gaynor, to seek a diagnosis. As a couple, they were offered eight post-diagnostic education sessions, the last of which focused on thinking ahead and planning for the future and introduced them to terms such as Lasting Power of Attorney and advance care planning. However, Ben and Gaynor were left unsure as to how to go about doing these, or indeed if Ben is able to be involved in the discussions due to his diagnosis. Gaynor is anxious as she does not want to make these decisions for him if he is still able to do so himself.

Ben's case highlights the uncertainty and emotional burden that can accompany young onset dementia (Knight and Pepper, 2024). Despite his diagnosis, Ben retains the right to participate in decisions about his future, including the creation of LPAs. This underscores the importance of timely, accessible post-diagnostic support that empowers individuals to plan ahead while they still have capacity (Couch et al., 2024).

Pre-empting the Future Loss of Capacity

To retain as much say about the future as possible, after a diagnosis of dementia, the diagnosed person can make provisions to appoint an attorney to make decisions for them if they lose capacity. The progressive erosion of cognitive functions caused by dementia may reduce capacity to make even the simplest choices, so timing is essential (Couch et al., 2024). LPAs can be made for both 'property and financial' decisions and for 'health and welfare' decisions with a separate legal document required for each type of power.

The Government advise that you do not always need to involve a lawyer or solicitor in developing an LPA, unless the person has unusual or specific requirements. However, the guidance does not qualify this statement by making any suggestions as to what requirements are deemed unusual, or which specific decisions require such attention (Office of the Public Guardian 2025). However, the MCA does affirm that a person with dementia has the right to make decisions that we might consider unwise though examples of such are very individual.

It is important that post-diagnostic information for families affected by dementia empower them with knowledge and resources to enable them to plan. Such information, for example, the fact that an attorney can only make a health and welfare decision if the person with dementia no longer has mental capacity to make the specific decision, is important to know when in the developmental stages of an LPA. Similarly, they should be informed that a person with dementia can consent to their appointed attorney to make financial decisions on their behalf before they lose mental capacity. In the case of Ben and Gayle, this information may serve to ease both party's anxiety on the role of decision making to reflect an approach to decision making that then becomes one of being shared, including the involvement of health and care professionals (Bhatt, et al., 2020).

It would be important to inform Ben and Gayle as they plan the LPA that it is difficult to mitigate all possible future decisions, especially LPA for health and welfare, and that there may be instances where a decision is needed on something that is not covered but that there are mechanisms under the MCA to support them. For example, the court of protection has power to appoint a deputy to make decisions which the individual cannot make or when making best interest for complex decisions or where there is dispute.

If Ben was unable to make his own decisions, and had not made his wishes and preferences known on a specific topic, or Gayle, as his wife, were unable or unwilling to support decisions on Ben's behalf, it may be appropriate to seek the appointment of an Independent Mental Capacity Advocate independent advocate (IMCA). The role of the IMCA would be to try and establish what Ben's wishes and preferences might have been. The IMCA is not the decision maker but considers the support for the person to decide for themselves, if possible, or to gain an understanding of their wishes, preferences, feelings, beliefs and values which will have a bearing on the decision. They can also consider what alternative courses of action are available, who else should be consulted, including whether any further medical opinion is required.

Case study 2

> Gregor and Zosia had been married for 42 years when Zosia was diagnosed with a mixed dementia of vascular dementia and Alzheimer's disease. Over the next four years they continued to live well as a couple, adjusting to the diagnosis with the support of their local Admiral Nurse. They both shared a wish that Zosia would remain living in their family home. However, over the last year Zosia's condition has progressed significantly and her general functioning has been affected. She is no longer able to wash and dress herself, even with prompts and coaxing from Gregor. She has become doubly incontinent and is resistant to the care of Gregor or that of the home care workers that come to support her. Their Admiral Nurse has gently been suggesting to Gregor that despite their original wish for Zosia to be cared for in their own home, this may no longer be possible. Gregor's main concern is for what Zosia would want, though he understands that Zosia no longer has the capacity to make such decisions.

Zosia's case, by contrast to Ben's, reflects the complexities of decision-making in more advanced stages of dementia, where capacity may be lost and best interest decisions may become necessary, especially if no prior advance care plan or advance decisions have been made. Gregor's concern for Zosia's wishes, despite her limited ability to express them, exemplifies the ethical imperative to consider the person's values, past preferences, and dignity (van der Steen et al., 2025). The MCA's best interest checklist provides a structured approach, but the emotional and relational dimensions that such decision-making presents to family carers cannot be overlooked (Mogan et al., 2022). Families affected by dementia require both support in decision making but also information about the nature of advancing dementia for such decision-making to be well informed (Cousins et al., 2022). Cousins and colleagues developed on-line training and a guide to support families in decision making for a person with advanced dementia, however, access to such information and support is often dependent upon professional facilitation. Community nurses are ideally placed to to enable this.

Deprivation of Liberty Safeguards (DoLS)

If the decision was made to admit Zosia to a care home, there may be other considerations, such as deprivation of liberty. Deprivation of Liberty Safeguards (DoLS) under the MCA are subject to approval by local authorities and are more often made in a care home setting, although they can apply in the person's own home but must be considered being in the person's best interests. Detention in a care home is likely to be for a long-term period, requiring fewer overall restrictions (a lighter touch) than someone who needs to be detained in a hospital for a short period of time for assessment or treatment of a mental health condition under the MHA.

In practice, the implementation of the MCA and associated safeguards, such as DoLS, requires ongoing education and reflective practice among community nurses and other health and care professionals. The dynamic nature of dementia, combined with the individuality of each person's experience, demands a flexible yet principled approach. As the prevalence of dementia continues to rise, so too must our commitment to upholding the rights, preferences, and dignity of those affected.

The case studies illustrate the real-world challenges faced by individuals and their families in navigating the implications of a dementia diagnosis. Both scenarios reinforce the need for shared decision-making, a process that respects the autonomy of the person with dementia while recognising the supportive role of carers and professionals (Liu et al., 2025). Shared decision-making is not merely a legal requirement but a relational practice that fosters dignity, trust, and person-centred care (Daly et al. 2018). Tools such as decision aids can facilitate this process (NICE, 2018), especially when capacity is borderline or fluctuating. Decision aids clearly state the decision in question, provide contextual information and summarise options including potential benefits and harms, and can be in a variety of forms including video, paper or web-based (Davies et al. 2019).

Conclusion

This article has explored the complex interplay between cognitive decline, legal frameworks, and ethical practice in supporting decision-making for individuals living with dementia and their family carers. The MCA provides a robust legal foundation for community nurses and other health and care professionals in assessing capacity and their support in guiding decision making for families affected by dementia. The practical application of the MCA requires nuanced understanding and sensitive implementation by all health and care professionals and legal practitioners alike that relates to the individual's and family carers' specific decision requirements across a range of care settings.

Key points:

- As a person's dementia progresses their ability to make independent decisions will be affected.
- Shared decision-making including the person with dementia, family carers and health and care professionals can enable the making of decisions that are in-keeping with a person's wishes and preferences.
- The MCA and its code of practice support decision making through its processes and guidance.

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Box 1: Guiding principles of a capacity assessment (adapted from MCA 2006)

1. The person must be assumed to have capacity unless it is established that they lack capacity.
2. The person must not be treated as unable to make a decision unless all practicable steps to help them to do so have been taken, without success.
3. The person must not be treated as unable to make a decision merely because they make an unwise decision.
4. An act done, or a decision made, under the MCA for someone who lacks capacity must be done, or made, in their best interests.
5. Consideration must be given to the best interest decision being enacted to the least restrictive impact of their rights and freedom of action.