

Dementia Gateway: Making decisions

Key messages

- There is not much research on the experiences of social care staff, and people with dementia and their carers within the context of the Mental Capacity Act (MCA) 2005 and dementia care.
- Staff in residential care settings can make false assumptions about incapacity based on negative stereotypes about disability.¹ Sometimes if a resident cannot communicate very well this can lead to their rights being denied.³
- There are significant variations in the ability of care homes to apply the terms and standards of the MCA.⁴ Some of these differences could be a result of staff roles and different levels of responsibilities.⁴
- Many professionals are uncertain about their legal responsibilities within the context of the MCA, despite Department of Health funding to provide training for health and social care staff.^{1,7}
- Some social workers say that the MCA is empowering as it has increased their confidence in their professional skills.⁸ Adult safeguarding work has also been given momentum by the MCA and its provisions for specific offences and through the optional introduction of the 'independent mental capacity advocate' (IMCA) role into safeguarding situations.⁹
- Publicity material for older people about the MCA is poor. GPs have a potential role in addressing this issue as they are generally a trusted source of advice for people.¹⁰
- Despite the potential of the MCA to safeguard (protect) the rights of vulnerable people, it is sometimes viewed as a complex law, which is difficult for the public to understand.¹³

Introduction

This summary highlights key messages from the research about making decisions for people with dementia, within the context of the Mental Capacity Act (MCA) 2005. It does not describe the detail of the Act, nor is it a full description of the related research. The material on which this summary is based was identified through focused searching of the literature published from 2008 to 2012.

The status of research

There is not much research on the early diagnosis of dementia and advance care planning.² The quality of evidence on advance care planning varies, which makes it difficult to draw conclusions on what works. Guidance and inspection reports by organisations such as the Care Quality Commission are available, but there is not much research on different care settings and the experiences of social care staff and people with dementia and their carers, within the context of the MCA and dementia care.

However, indications are that early diagnosis gives people with dementia the opportunity to express their wishes for future care, and to make sure (by using the MCA) that their wishes have great weight in decision making in the future. Advance care planning has the potential to prevent unwanted hospital admission and so reduce healthcare costs for people with dementia and cognitive impairment (difficulty with things like remembering, learning new things, concentrating or making decisions).⁵

The Mental Capacity Act (MCA) 2005

'Mental capacity' refers to people's ability to make specific decisions at the time they need to be made.⁶ The first principle of the MCA is that all people are able to make decisions for themselves unless proven to the contrary.⁴ People may choose to use the MCA to make advance decisions to refuse treatment or to appoint decision makers for health and social care, property and financial decisions using 'lasting powers of attorney'.^{9,10} The MCA established specialist advocacy roles (that is, 'independent mental capacity advocates' – IMCAs) for isolated people who lack capacity in certain situations [9], including those who are subject to, or being assessed for, the Deprivation of Liberty Safeguards (see below). The MCA protects a person with dementia from assumptions that others make based on stereotypes and emphasises a person's rights, abilities and wishes.¹²

Which care staff does the MCA apply to?

The MCA was fully implemented in England and Wales in October 2007 and applies to all health and social care staff who are responsible for the care and treatment of people who may lack capacity to make decisions for themselves. The Act covers people with dementia, who are likely to lose capacity at some stage.⁴

Involving significant others in decision making

Where a person is assessed as being unable to make a certain decision, there is no relevant advance decision and nobody else has the power to make the decision (such as a lasting power of attorney), the Act stipulates that professionals involve him or her in decision making along with those who have an interest (such as family and friends) in the welfare of the person who lacks capacity to help to inform care decisions in the individual's best interests.^{3,9,14} The views of a GP and senior community or care home staff may also form part of best interest decision making.¹⁴

Deprivation of Liberty Safeguards (DOLS)

The Deprivation of Liberty Safeguards are an extension of the MCA. For older people with dementia they provide a framework by which it is only lawful to deprive an individual of their liberty in a hospital or care home, if it is in their best interests and when no less restrictive way to keep the person safe can be found.¹²

Some findings from the research

This section outlines some findings from the research on making decisions within the context of the MCA.

Staff assuming incapacity

Staff in residential care settings can make false assumptions about a person's inability to do things

based on negative stereotypes about disability.¹ Sometimes if a resident cannot communicate very well, this can lead to their rights being denied.³ These issues are apparent in cases where care home staff have taken decisions about things such as finances on behalf of disabled residents (dementia not specified) without checking beforehand to see whether residents are able to make those decisions on their own.¹

Variations in ability to apply principles and standards of MCA

There are significant variations in the ability of care homes to apply the terms and standards of the MCA.⁴ Some of these differences could be a result of staff roles and different levels of responsibility, but this is not always the case.⁴ It appears that some staff are applying the principles using a 'common sense' approach without a proper understanding of them.⁴

On the other hand, coordinators involved in adult safeguarding (protection) work have successfully put the principles of the MCA into their practice and systems at work and they have provided an important source of expertise for local professionals and communities.⁹

Confusion about responsibilities

Many professionals are uncertain about their legal responsibilities within the context of the MCA, despite Department of Health funding to provide training for health and social care staff.^{1,7} For example, staff may have been wrongly told that assessing someone's capacity is not within their remit, but the duty of a consultant psychiatrist or director of nursing.¹⁵

Building the capacities of staff

While some health and social care staff do not see the need to comply with the Act as a priority,¹⁵ social workers say that the MCA is empowering as it has increased their confidence in their professional skills.⁸ Adult safeguarding work has also been given momentum by the MCA and its provisions for specific offences and through the optional introduction of the 'independent mental capacity advocate' (IMCA) role into safeguarding situations.⁹

Looking for information and guidance about the MCA

Many care home managers are confident about where they would go to for advice about putting the MCA into practice.⁴ Sources of advice vary and include a senior manager; a regional manager if appropriate; a social worker; community mental health nurses; the local health team; the IMCA helpline; solicitors; local voluntary organisations; and GPs.⁴ Safeguarding adults or adult protection coordinators (in a specified area) have looked for support from a combination of sources, including the local authority's legal department; the local authority MCA lead; heads of department, practitioners or psychiatrists; various networks such as the local MCA implementation group; the Department of Health; codes of practice and other material; and the internet.⁹

Publicity and information

Staff involved in the safeguarding (protection) of adults have been concerned that material published by the Office of the Public Guardian when the Act was launched has been discontinued; and

electronically downloadable information from its website was often inaccessible.⁹ This situation has now changed and material is accessible at www.justice.gov.uk/about/opg

Role of voluntary organisations

Alzheimer's Society and carers' organisations have felt that their role includes giving advice and information to people with dementia and their carers, but have felt unqualified to give detailed legal advice on the MCA and so they have referred people on to solicitors instead.¹¹ For this reason, health and social care professionals need to be aware of local variations in expertise within voluntary organisations advising about the MCA, as this has implications for people with dementia and their carers who are referred to such services.¹¹

The public's interpretation of the MCA

Despite the potential of the MCA to safeguard (protect) the rights of vulnerable people, it is sometimes seen as a complex law that is difficult for the public to understand.¹³ Publicity about the MCA aimed at older people is poor, and GPs have a role in raising awareness and advising older people, who generally see them as a trusted source of advice.¹⁰ All other care workers also have a role in this respect.

Implications from the research

The initial implementation of the MCA (and the related Deprivation of Liberty Safeguards) has only gone some way in helping the process of decision making by people lacking capacity, promoting their best interests and protecting their liberty. Future implementation needs to make sure that the rights of people with dementia (and others lacking capacity) are given more priority in health and social care and are better protected through using the MCA.³

Training covering the principles of the MCA needs to be promoted, bringing the added benefits of improved staff morale and better recruitment and retention of staff in dementia care.¹⁶

Health and social care professionals need to be aware of local variations in expertise within voluntary organisations advising about the MCA, as this has implications for people with dementia and their carers who are referred to such services.¹¹

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