



Mental Capacity and Healthcare



Adults with learning disabilities or suffering from dementia, brain injuries or mental illness may be unable to make health decision for themselves. At such times, others will need to decide in their place. The Mental Capacity Act (2005) (hereafter 'MCA') provides a substitute decision-making framework. It exists alongside another such framework – the Mental Health Act (hereafter 'MHA') 1. While the MHA is restricted to compulsory treatment for mental disorder, the MCA has a broader scope. It applies to physical and mental health as well as to welfare, finances, property and research participation. This POSTnote outlines how the MCA is being interpreted in healthcare and how it works alongside the MHA.

Background

Imagine a person with schizophrenia who has diabetes. He has delusions he is a world famous surgeon. The diabetes is affecting a foot and the foot has become gangrenous. A surgeon recommends amputation but the patient refuses. Alternatively, imagine a young woman with complications following a car accident. She belongs to a family with a religious belief that accepting a blood transfusion is sinful. A doctor recommends a transfusion but the patient and her mother refuse. The question is who decides and how is a decision reached. In England and Wales, before the MCA, such decisions came under the common law². This consisted of a number of judgements made by the Family Division of the High Court, the Court of Appeal, and the House of Lords all of which were based on the principle that adults decide for themselves (personal autonomy) unless unable. While healthcare practice had to operate according to these common law judgements, historically it has been guided by more paternalistic concepts of duty of care without a strong legal awareness. Outside of hospitals,

Overview

- The Mental Capacity Act (2005) has provided clarification on the scope of the basic concepts of decision-making capacity and best interests. While these are not new concepts in healthcare, different areas of practice are likely to need more time to interpret them in real life settings.
- Anticipatory decision-making is a newer part of medical law and healthcare experience. Health professionals are positive about advance healthcare planning except with regard to possible inflexibilities. It has not been tested much either in case law or in everyday healthcare practice.
- The Act has been in operation for 3 years, a short time over which to assess the impact of legislation which took 16 years to develop.
- There is a tension between the Mental Capacity Act and the Mental Health Act.

however, for many carers of people with learning disabilities, dementia or mental illness, concerns were expressed about the lack of legal guidance. The MCA was developed against this background (Box 1).

Box 1. History of the Mental Capacity Act

In 1989, the Law Commission, motivated by concerns from carers, started a project to clarify the common law and develop a new legal framework to protect adults unable to decide for themselves as well as the people who acted for them. This was based on the principle of personal autonomy and on enabling autonomy wherever possible. It received widespread support and in 1997 the Lord Chancellor took it forward with a Green Paper³. In 1999, the then Department of Constitutional Affairs issued the policy statement *Making Decisions* (1999, Cm 4465) to reform the law. A draft Mental Incapacity Bill was published for pre-legislative scrutiny in 2003. A joint parliamentary scrutiny committee was set up to report on the draft bill. This made recommendations, most of which the government accepted and the Mental Capacity Bill was introduced to the House of Commons in 2004. It received Royal Assent in 2005 as the Mental Capacity Act thereby completing a 16 year process of law reform. It is the responsibility of the Justice ministry and not Health.

General Reception of the Act

At bill stage the MCA was regarded as a highly significant piece of legislation in healthcare⁴. It developed, in spirit, recommendations made by leading reports on medical ethics⁵. Some people emphasised its continuity with the past: it codified the common law on matters relating to health and also modified the old Court of Protection and Public Guardianship Office. Others emphasised the more fundamental changes it introduced, even likening it to the Human Rights Act⁶. For instance, the MCA:

- formalised a substitute decision-making scheme for healthcare based on personal autonomy and created a new Court of Protection, equivalent in status to the High Court;
- extended powers of attorney to health and welfare decisions and introduced the concept of “Deprivation of Liberty” in healthcare settings.

The implementation group at the Department of Health report that the MCA has been a challenge to pre-existing cultures in healthcare. Initially, the act made many practitioners feel unsure whether their prior understanding of the common law was correct. Some practitioners praise the clarifying effect of the act; others feel like it gets in the way of treatment. It is based on three fundamental concepts: decision-making capacity, best interests and anticipatory decision making.

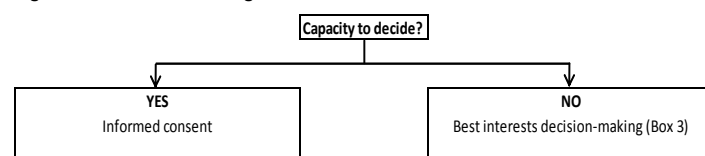
Decision-making Capacity

The MCA presumes ability to decide, but when this is in doubt, requires assessment of decision-making capacity. The assessment determines whether a healthcare professional needs to act in an individual’s best interests or in a way that respects informed, freely given, patient choice (see Figure 1).

Following the common law, the MCA frames mental capacity as a test of the impact of a mental disorder on a decision-making process that faces a person. It tests ability to decide in terms of both an ability to understand relevant information and an ability to make decisions on the basis of that understanding (see Box 2). It is not a test of a person’s status (such as soundness of mind)⁷ or of the eccentricity of someone’s decision (such as a refusal of a conventional treatment). For example, a person with Alzheimer’s disease may have problems understanding or retaining information, whereas one with severe depression or schizophrenia may have problems using or weighing that information in the process of deciding. The test thus covers the decision-making problems people with learning disabilities, dementia, brain injuries or mental illness may have, without assuming that these problems affect all their decisions.

This is not a new concept for some healthcare professionals. For instance, for those working in old age medicine or learning disabilities, the MCA generalises the common law approach and makes it more explicit. Furthermore, its impact can be assessed reliably⁸. Research has shown incapacity for healthcare decision-making to be common in acute wards of general hospitals with rates fairly

Figure 1. Decision-Making Within the MCA



Box 2. Testing the Ability to Decide

People are unable to make a decision for themselves if they cannot:

- understand the information relevant to the decision
- retain that information
- use or weigh that information as part of the process of making the decision
- communicate any decision (whether by talking, using sign language or any other means).

Source: Mental Capacity Act (2005) section 3(1)

similar to those of mental health hospitals but with different underlying causes. In general hospitals, there is a tendency for incapacity to go unrecognised⁹.

In acute mental health hospitals the MCA exists alongside the MHA. The MHA is not capacity based, but there is evidence that most people detained under it in such hospitals lack a capacity to make treatment decisions, against only 1 in 3 of those who are not detained.¹⁰ Outside hospital, less evidence is available.

Few healthcare professionals express specific concerns about the assessment of capacity although questions about how to approach “fluctuating” capacity remain. Many healthcare professionals see the capacity test as a helpful clarification that:

- decision-making capacity is not a status affecting all decisions
- assessment is a generic skill that relates to decisions involving *all* healthcare professionals – from simple acts of care to highly technical surgery.

Most training so far has involved transferring knowledge of the law but interpretation of real clinical cases is now identified as a real need.

Best Interests

Best interests describes the legal framework that regulates healthcare professionals and carers when a person lacks capacity to make a health decision. The MCA does not define “best interests” but rather provides a set of checks on the process of deciding what they are (see Box 3). In relation to healthcare it aims to implement two basic ideas:

- that treatment for the person should be the least restrictive of liberty
- that it should aim to be what the person would have wanted if they had had capacity to decide (Box 3).

If the treatment the person would have wanted can be discovered indirectly (e.g. through friends/family or an independent mental capacity advocate) this should have influence in identifying best interests, as should the present feelings and beliefs of the person.

In emergency situations, the MCA defaults to saving life. Outside of this, it places a check on any healthcare decision

Box 3. Check List for Best Interests

The MCA (2005) and associated Code of Practice state that:

- Working out what is in a person's best interests cannot be based simply on age, appearance, condition or behaviour.
- All relevant circumstances should be considered when working out best interests.
- Every effort should be made to encourage and enable a person who lacks capacity to take part in making the decision.
- If there is a chance that a person will regain the capacity to make a particular decision, then it may be possible to put it off until later if it is not urgent.
- When the determination relates to life-sustaining treatment he must not, in considering whether the treatment is in the best interests of the person concerned, be motivated by a desire to bring about his death.
- A person's past and present wishes and feelings, beliefs and values should be taken into account.
- The views of other people who are close to the person who lacks capacity should be considered, as well as those of an attorney or deputy.

makers' "I know best" instinct or on any tendency to assume that family members can consent for an incapable adult. This shift toward broader-based decision-making has been under way in healthcare for over a decade, with the development of multi-disciplinary teams and the explicit involvement of families in the decision-making process.

People experienced in teaching the "best interests" concept to healthcare professionals say that historically, best interests decision making has been "a coalition of professionals" and that the new best interests concept somewhat challenges this¹¹. The MCA expects there to be a best interests decision-maker and a best interests decision-making process, and aims to put the patient at the centre. Because modern healthcare teams are multi-disciplinary, the 'decision-maker' is the team member whose expertise is most suited to the decision. Managing this can cause confusion if teams are not well constituted or where local agreements are not in place.

Most of the Court of Protection's judgments on healthcare concern best interests. This is an evolving body of case law and within the last year it has been made available on the internet¹². The question of how to balance restraint against freedom from restraint, in someone's best interests, is a frequent theme of the cases. A recent example concerned a person with a learning disability and a phobia of hospitals who was refusing cancer surgery.

Anticipatory Decision-Making

One of the ways the MCA aims to enable autonomous decision-making is to encourage people's planning of their healthcare for times when capacity to decide is lost. There are two ways of doing this which are legally binding upon the healthcare provider:

- advance refusal of treatment
- appointment of a lasting power of attorney for healthcare.

Advance Refusal of Treatment

In an advance refusal of treatment, a Jehovah's Witness, for example, may draft an advance rejection of blood products.

A person with views about the end stage of dementia may draft an advance refusal of types of life sustaining treatments with their GP. The advance refusal of treatment binds future healthcare providers unless they can give reasons why the refusal is invalid or inapplicable in those particular circumstances. The MCA only clarifies the common law position here. There is, however, very little case law on advance refusals of treatment. The Royal Colleges of Physicians, Psychiatrists, General Practitioners, Nursing and the British Medical Association suggest that there are not many advance refusals around and few that can be readily interpreted in practice.

Prior to enactment of the MCA there was considerable concern about the potential for "Euthanasia by Omission" with advance refusals¹³. Over the last 3 years, such levels of concern have not existed in the healthcare arena, except in one case (Kerrie Woolterton) in 2007. This involved a young woman with a borderline personality disorder who swallowed a lethal amount of anti-freeze and self-presented to A&E with a written statement refusing life saving kidney dialysis and requesting only palliative care. She received the palliative care and died. Although she was, at the time of admission, thought to be capable of refusing, uncertainty has persisted about such refusals where anticipatory decision-making¹⁴ is involved. The Department of Health viewed the MHA as a possible resolution to such legal and clinical difficulties. Under it, anticipatory decision making does not have legal force and adults with the capacity to decide mental health treatment can be treated compulsorily.

Lasting Power of Attorney (LPA)

LPA for health is a new legal intervention introduced by the MCA (see Box 4). Approximately 38,000 LPAs for health and welfare are expected to be registered with the Public Guardian in 2011 and the trend for use of powers of attorney in general is a rising one¹⁵. Currently, the majority of these applications are being made by the elderly and include a decision-making power over life-sustaining treatment. The Public Guardian Board has reviewed the workings of LPAs over the last 3 years. It reports that "an ultimate measure of success for the MCA would be for every adult to have an LPA"⁵. LPAs extend to health the legal powers which previously have only applied to property and finance.

Box 4. Appointing an LPA for Health

A person can nominate a relation or friend (one or more) to become their best interests-decision maker for health. This makes them their health attorney. The LPA switches the duty to work out best interests for health away from the healthcare professionals to an attorney and creates a clinician-patient relationship that is legally mediated by a third party. The House of Lords Select Committee on Medical Ethics in its 1994 report recommended against this power⁴ while in 1995, the Law Commission report supported it (Law Com No 231).

The impact of this new power has yet to be felt on the ground. In the USA, where healthcare proxies exist in most jurisdictions, a systematic review has shown that proxies, when appointed by capable adults, predict patient treatment preferences only with 68% accuracy¹⁶. LPAs for healthcare

introduce significant shifts in identifying the duty bearer to decide on behalf of people unable so to do. The introduction of the family or friend as a formal legal third party in healthcare changes the relationship between the clinician and patient and between the patient and the state. It is too early to assess the impact of the LPA for health.

Relationship with Other Law

The MCA exists alongside the European Convention on Human Rights (hereafter 'ECHR') and the MHA. New safeguarding provisions were added to the MCA in 2007 following a judgement (known as "Bournemouth") of the ECHR¹⁷. New community treatment orders, involving the MCA, were added to the MHA in 2007.

Deprivation of Liberty Safeguards (DoLS)

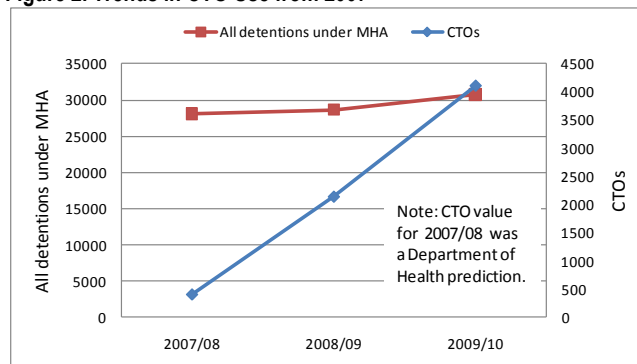
The "Bournemouth" judgment involved a patient with autism and severe learning disability where communication broke down between the healthcare team and the carers. The patient was receiving health care in hospital informally (i.e. not under the MHA) without capacity to decide but without objection. The European Court of Human Rights judged that the care conditions amounted to a "Deprivation of Liberty" under article 5 of the ECHR and therefore required a safeguarding procedure prescribed by law. Subsequently DoLS have been included in the MCA to achieve compliance with the ECHR.

Professionals with experience of these procedures view them as complex, time consuming and offering weak safeguarding (local authority monitoring). Costs have been mentioned as a concern both by the Court of Protection (which oversee the procedures) and by health service researchers¹⁸. Currently, applications for DoLS have been well below expected levels. It is possible that this is because of difficulties interpreting "Deprivation of Liberty" in healthcare settings; expert lawyers have difficulty agreeing if a case has occurred¹⁹. DoLS differ from the rest of the MCA in that they place the emphasis on gaining the authority for a care approach. In contrast, the remainder of the MCA places the emphasis on giving a justification for a care approach with streamlined, informal, safeguards²⁰. When detention amounting to a "Deprivation of liberty" is involved, healthcare providers may prefer the stronger authorisations, safeguards and administratively more streamlined procedures offered by the MHA.

Community Treatment Orders (CTOs)

CTOs stipulate conditions for people with mental disorders in the community (e.g. taking medication) and allow a recall to hospital under conditions involving health, safety and the protection of others. Their use has exceeded expectations in the first three years alongside a steady rise in the use of the MHA (see Figure 2). For a person on a CTO in the community, the MCA applies in name (including anticipatory decision making) but the recall to hospital follows MHA rather than MCA principles. If recalled, the MCA is trumped.

Figure 2. Trends in CTO Use from 2007²¹



Because the MCA applies to adults in the community who are leaving hospital after having been 'sectioned' under the MHA, healthcare systems face a choice. On the one hand they could steer away from CTOs and treat persons lacking capacity in their best interests without invoking the MHA. On the other hand, they could steer toward the framework of the MHA with its inherent compulsory powers. Currently, at least, the trend is towards the MHA. There is evidence to suggest that this trend may not deliver better outcomes at a population level²².

Substitute Decision-Making after the MCA

The introduction of the MCA does seem to have made it clearer that a tension exists between two legal traditions for substitute decision-making in health: one that is based explicitly on the principle of capacity and personal autonomy (now the MCA) and one that is not (the MHA). The MCA and the MHA now exist side by side and both can apply to the same person. When these two structures meet - in anticipatory decision-making, in deprivation of liberty and in community treatment orders - there is evidence of complexity and confusion. Case law is evolving in these areas but it is unlikely to provide an easy legal fix.

Endnotes

- Both the Mental Capacity Act (2005) and the Mental Health Act (1983) were amended by the Mental Health Act (2007). By 'MCA' and 'MHA' we refer to the original Acts with all subsequent amendments.
- Re C* [1994] 1 All E.R. 819; *Re T (Adult)* [1992] 4 All ER 649
- Who decides? (1997, Cm 3803)
- Hansard HL* 10 January 2005, cols 11-106
- Report of the Select Committee on Medical Ethics* HL Paper 21-I date
- The Public Guardian Board's Annual Report 2010, p13.
- ECHR article 5 (1e)
- Okai, et al. (2007) *British Journal of Psychiatry*, **191**, 291-97
- Raymont et al. (2004) *Lancet*, **9443**, 1421-27
- Owen, et al. (2008) *BMJ* **337**: a448.
- MCA Implementation Manager, Department of Health
- <http://www.bailii.org/>
- HC library research paper 04/73 (2004)
- David, et al. (2010) *BMJ*, **341**, 587-91
- Court of Protection figures
- Shalowitz et al. (2006) *Arch Intern Med*, **166**, 493-97
- HL v UK* 45508/99 (2004) ECHR 471
- G v E Ors* [2010] EWCA Civ 822 at para 74 and 76
- Cairns, R. et al. (2011) *The Psychiatrist* (In Press).
- Section 5/6, MCA
- Health and Social Care Information Centre (Oct. 2010)
- International Experience of Using CTOs, Department of Health (2007); *Cochrane Database of Systematic Reviews* (2011), Issue 2, CD004408.