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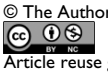
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Making healthcare decisions in a person's best interests when they lack capacity: clinical guidance based on a review of evidence

Derick T Wade[1] and Celia Kitzinger[2]

Abstract

Objective: To clarify the concept of best interests, setting out how they should be ascertained and used to make healthcare decisions for patients who lack the mental capacity to make decisions.

Context: The legal framework is the Mental Capacity Act (MCA) 2005, which applies to England and Wales.

Theory: Unless there is a valid and applicable Advance Decision, an appointed decision-maker needs to decide for those without capacity. This may be someone appointed by the patient through a Lasting Power of Attorney, or a Deputy appointed by the court. Otherwise the decision-maker is usually the responsible clinician. Different approaches exist to surrogate decision-making cross-nationally. In England and Wales, decision-making is governed by the MCA 2005, which uses a person-centred, flexible best interests (substituted interests) approach.

Observations: The MCA is often not followed in healthcare settings, despite widespread mandatory training. The possible reasons include its focus on single decisions, when multiple decisions are made daily, the potential time involved and lack of clarity about who is the responsible decision-maker.

Solution: One solution is to decide a strategic policy to cover more significant (usually health-related) decisions and to separate these from day-to-day relational decisions covering care and activities. Once persistent lack of capacity is confirmed, an early meeting should be arranged with family and friends, to start a process of sharing information about the patient's medical condition and their values, wishes, feelings and beliefs with a view to making timely treatment decisions in the patient's best interests.

Keywords

Mental capacity, decision-making, best interests

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[1]Professor of Neurological Rehabilitation, OxINMAHR, and Movement Science Group, Faculty of Health and Life Sciences, Oxford Brookes University, Oxford, UK
[2]Honorary Professor and Co-Director of the Coma and Disorders of Consciousness Research Centre, School of Law and Politics, Cardiff University, Cardiff, UK

Corresponding author:
Derick T Wade, Professor of Neurological Rehabilitation, OxINMAHR, and Movement Science Group, Faculty of Health and Life Sciences, Oxford Brookes University, Headington Campus, Gypsy Lane, Oxford OX3 0BP, UK.
Email: derick.wade@ntlworld.com;
Twitter: @derickwaderehab

Introduction

In England and Wales, the Mental Capacity Act (MCA) 2005[1] was passed in order to protect clinical staff from legal action for assault, battery or civil trespass when delivering treatment to patients deemed to lack the mental capacity to give consent. Failure to adhere to the Act, and its associated Code of Practice leads to the following:[2]

- Leaves the clinicians and hospital liable to legal action;[3]
- Is criticized in courts;[4,5]
- Is likely to cause distress to family members;[6]
- Is contrary to ethical and professional standards;[7]
- May breach a person's human rights.

However, many years on, widespread failure to adhere to the Act is common.[8,9] The UK House of Lords reviewed the implementation of the Act in 2013.[8] It concluded that there was a complete failure to embed the Act in everyday practice, and a low awareness of the Act among those affected. A systematic review of studies of the Act's implementation[9] found that training of staff, which is mandatory, was usually implemented but that understanding and implementation of the Act was generally poor. One strong theme was the difficulty of applying it to clinical practice. One reason for this may be the lack of clinically focused guidance, which this article offers.

This article discusses the best interests decision-making process across the full range of medical decisions in adults aged 18+ years, covering the following:

- *Why* an authorized way to make decisions is needed, and various approaches that have been developed;
- The details of the 'best interests' approach used in the MCA 2005;
- *How* these principles can be enacted within clinical practice, *with* further aide memoires available as supplementary materials (Figures 1 and 2, and Table 1).

The article is predicated on a proper assessment of a person's mental capacity to make a decision, which is discussed in the companion article.[10] It also draws on the recently published guidance for England and Wales on decisions about gastrostomy feeding.[11]

Background legal/ethical considerations

The first half of this article sets out the legal and ethical considerations, explaining the principles behind the best interests process and discussing some of the problems and difficulties that have been raised. This is important because an awareness of these matters is likely to improve the understanding and use of the legally required best interests process.

Legitimizing healthcare and treatment

The legitimacy of most healthcare interventions depends upon the patient's consent[12] In order to consent, the person requires the mental capacity to understand information relevant to the healthcare decision that needs to be made, to remember it long enough to consider it in relation to their own situation and to weigh up the pros and cons of treatment, and the ability to communicate the decision, with support if necessary.[10]

Even after losing capacity to make their own healthcare decisions, people may retain control over decisions through an Advance Decision (to refuse treatment).[1] (Similar instruments with different names exist internationally, e.g. Advance Directives in the United States and in Scotland (where they are not statutory) and Advance Healthcare Directive in Ireland). The 'Decision' or 'Directive' is made while the person has the capacity to make their own healthcare decisions and specifies what interventions the person has refused in what potential future circumstances, if that capacity were to be lost.[13,14] In England and Wales an Advance Decision is legally binding on the healthcare team, provided it is valid and applies to the situation.[1]

There is evidence that healthcare teams do not always comply with an Advance Decision,[15,16] but other evidence suggests that – even so – they can

Box 1. Failure to comply with valid and applicable advance decision.

Reasons:
- Non-availability of Advance Decision to clinical staff
  - No national repository
  - Limited electronic access[18]
- Poorly written
  - Unnecessary legal language
  - Hard for healthcare professionals to understand[19]
- Uncertainty about validity or applicability[20]
  - Including widespread misunderstanding[21]
- Ignorance about law and medical practice relating to Advance Decisions[18]
- Conscientious objection to withholding/withdrawing treatment[19]
- Fear of allowing death

Consequences:
- The healthcare team is not acting within the law;
  - May be legally liable for assault, battery, civil trespass
- The patient receives treatment they refused
  - And may lose the 'window of opportunity' for death
- There is a breach of autonomy and patient-centred care
- Family may be devastated that loved one's wishes are overridden

have a major influence on the care given.[17] Failure to comply may arise for several reasons, and has consequences – see Box 1.

The patient may also influence decisions after losing capacity through granting a Lasting Power of Attorney,[1] empowering the person they have chosen to make healthcare decisions on their behalf in their best interests when they lack capacity.[22] The person can authorize the attorney or attorneys to make all decisions concerning health and welfare, including 'life and death' decisions, or can restrict them to making only specified decisions.

If the person lacking capacity has not already appointed an attorney for health and welfare, someone else may apply to be a deputy; the application is considered by a court that may appoint the applicant to be a health and welfare deputy. A deputy must, like an attorney, make decisions in a person's best interests, but unlike an attorney, the powers of a court-appointed deputy can *never* include stopping life-sustaining treatments.[23]

Last, a person may make an Advance Statement about their wishes.[1,24] These statements are not legally binding, but set out the factors that a person wishes to be considered when others make healthcare decisions on their behalf and any such statements must be considered as a part of best interests decision-making. Such statements can be the only form of advance planning, or can be used in conjunction with an advance decision or surrogate decision-maker. They can help decision-makers if, for example, an advance decision is found inapplicable to a situation, and can guide an attorney or deputy when making a decision.

Surrogate decision-making: comparing 'substituted judgement' and 'substituted interests'

There are many different approaches to surrogate decision-making. Phillips and Wendler[25] identify five. Three of these are closely related to one another: the 'Substituted interests' (promote the patient's best interests); 'Authentic life' (continue the patient's previous lifestyle as closely as possible) and 'Endorsed life' (promote the life the patient valued). A fourth option is the 'Substituted judgment standard' (make the decision the patient would have made) and the last approach is 'Family interests' (promote the family's interests).

A strict family interests approach may ignore the patient's wishes and autonomy and will be discounted here. Nevertheless, the family does have legitimate interests. The patient may have wished to consult family members about serious health decisions.[26] The decision may have an impact on the family, and the patient may well have taken that into account.[26,27] Thus, the primary distinction now is probably between the Substituted Judgment Standard and the Best (or substituted) Interest Standard.[28]

The substituted *judgement* approach, first used in England in 1815,[25] seems simple – people who know the patient make the decision the person would have made in the present situation. Various practical and philosophical difficulties have been identified. Is it possible to imagine what a

competent incarnation of the person would decide when a vital fact about his state is that he is now incompetent?[25] How can any doctor trust the opinion given by another person about the patient, without first being given evidence to support the opinion?[29] A person's expressed choice may change when in new circumstances.[30] If someone lacking capacity seems happy in their new situation, should views about healthcare decisions expressed by their former self override their apparent current wishes[31] or not?[32] Can this approach apply to someone who has never had capacity, such as an infant or any person with lifelong severe learning disability? Last, the people who give an opinion on a patient's likely decision may feel responsible and guilty, which may influence what they say.[25]

The substituted *interests* approach[33,34] does not require family and friends to express an opinion about the decision a person would have made. Instead they are asked to explain what factors would have been used by the patient (their interests) and how the patient would have arrived at a final decision, for example, by consulting family members. Thus, once this information is available, the clinicians together with family and friends consider the clinical facts and use the factors and methods the patient would have used to reach a decision.

In order to remove the uncertainties associated with a person-centred approach, some people suggest that decisions should be based on criteria and weights derived from socially agreed constructs such as maintaining dignity, minimizing suffering, and prolonging life.[26] There are two difficulties with this approach. What is the appropriate society to consult: friends, family and acquaintances; religious associates; people in some limited locality, people from the same ethnic group, the whole nation? Second, how is the view of the society ascertained and melded into one, and how often should that be done? It is not a practical proposition.

Thus, while there is no completely coherent, philosophically and logically defensible system that can cover every eventuality, the broad best interests approach used within the MCA is often considered to be the most useful approach as it allows, in theory, for integration of both patient autonomy and likely wishes with aspects of substituted judgement and family interests.[28,35] As Lady Hale wrote,

> But the best interests test should also contain 'a strong element of "substituted judgment"', taking into account both the past and present wishes and feelings of patient as an individual, and also the factors which he would consider if able to do so. This might include 'altruistic sentiments and concern for others'.[36] (para 24)

Best interests in the MCA: law and practice

The MCA[1] lists the person's interests that must be considered as follows:

1. 'The person's past and present wishes and feelings';
2. 'The beliefs and values that would be likely to influence his decision if he had capacity';
3. 'The other factors that he would be likely to consider if he were able to do so'.

Legal judgements have made it clear that the strong presumption in favour of 'sanctity of life' (i.e. staying alive and living for as long as possible) can yield when sufficient evidence reveals that this conflicts with the wishes of the person.[37] The Act further stipulates that those to be consulted include

1. Any attorney or deputy involved;
2. Any person named by the patient as someone to consult;
3. 'Anyone engaged in caring for the person or interested in his welfare'.

The Act is based on an all-encompassing view, both of what might be relevant in the decision-making process and of who should be consulted. The Act does not dictate which factors should be considered or ignored in a particular case, nor does it give any guidance on the relative importance of particular factors. The Act does not restrict who should be asked for information, and it may include both a wide range of

family members and any others who have an interest in the patient.

The concept of best interests has been criticized for 'its vagueness and thus the inadequate guidance it offers to care providers'.[38] It is true that the words used in the Act, such as 'wishes and feelings', are difficult to define. Moreover, the Act does not explain how to determine what weight or importance should be given to any particular factor.

These apparent weaknesses are in fact the Act's main strength. Its concern is to make the decision-making process person-centred, by trying to reproduce the process the person would have used.[36] It is unlikely that any two people will consider exactly the same factors or give them the same relative importance. The Act is therefore acknowledging that there is no algorithmic way to make a decision, other than considering the person's likely approach. As has been written, 'It is intended to be dynamic and responsive in its operation'.[39]

One concern, arising from the problem expounded in detail by Dworkin,[31] relates to wishes and feelings: to what extent can a person's current wishes and feelings be ignored when lacking capacity?[32,39] The Act addresses this concern by stating that both past and present wishes and feelings should be considered. If past and present wishes and feelings differ sufficiently to affect the decision, then the clinical team (or a court) will need to consider their relative importance in the particular circumstances.[40]

When the person cannot communicate, their current wishes and feelings cannot be known and so only premorbid wishes and feelings can be used. It has been argued that a person might have different views if or when they recover sufficiently to express them in the future and that therefore decision-making should be delayed pending determination of their future views. In one case, this argument was lost,[37,41] but it remains an open argument.[40]

Most of the other concerns relate to discovering what factors a person thought important, and how these are used to arrive at a decision. The complexity of making healthcare decisions is demonstrated in the companion paper on mental capacity.[10] It follows on from the inevitable uncertainties, the multiple unpredictable consequences of each factor and the different weights each person will use. Furthermore, no one will actually work through all the factors to reach a rational decision (i.e. based on summing all the positive and negative consequences after giving values to each one). Instead, most people will consider one or two aspects of the available information and use some general rules or values to reach a decision.

We can never achieve a complete understanding of how any person would reach a conclusion, nor can we even know all the information a person would use and what importance he would give to each item. Nonetheless, it seems likely that most people will have a general disposition towards a certain style for making decisions and rely on a certain small set of important values or attitudes. Furthermore, to a variable extent, most people will also be influenced by their family and by general social attitudes and values.

If the paragraph above is accepted, then we should accept that, even with incomplete information, we should be able to approximate the relatively few factors a person would rely on, and their general disposition when making decisions. Furthermore, we should acknowledge families' and friends' views and applicable cultural views as relevant, within limits derived from the patient (e.g. taking note of whether the individual has broken with their family's religious or cultural traditions and followed a different path). Among the broader cultural influences to be considered are such matters as respect of the individual, maintaining dignity and consideration of their life's narrative[26] – what sort of life did the person live and how would that influence any decision when considering the potential outcomes.

In conclusion, the best interests approach is an exercise in being as person-centred as possible with all the uncertainties and difficulties that implies. The holistic and person-centred approach was succinctly set out by Mr Justice Charles, who said (para 57) that a best interests test 'requires the decision maker to perform a weighing or balancing exercise between a range of divergent and competing factors' and (para 58) that the decision is influenced by 'the force, clarity or certainty of conclusions' and that 'competing factors will affect

the weight to be given to them and that the weighing exercise is not a linear or binary exercise'.[37] Other examples from court judgements can be found on pages 63-64 of recent guidance concerning application of the process to decisions about life-sustaining treatment.[11]

A decision – or a policy?

The Act,[1] its Code of Practice,[2] and most documents and discussions about it are framed in the context of making a single decision, which does not reflect reality within the healthcare system or social care[42] where many actions are undertaken each day, each requiring consent. The Act implies that each action should be considered independently, because capacity is decision-specific, which would be very costly in terms of time and effort.

The difficulties of using and interpreting the Act in the care of people with lifelong disorders have been discussed:[43,44] One suggested solution is to separate out minor day-to-day decisions (tactics) from a long-term policy (strategy).[42] Healthcare decisions are placed in the strategic category.

If one considers anyone who has lost capacity and is unlikely to regain it in the short-term, the healthcare decisions and situations faced can be categorized reasonably easily into 'immediate', 'urgent' and a variety of 'elective' decisions.

A. *Immediate* decision, in a life-threatening situation such as cardio-respiratory arrest.
B. *Urgent* decision, in a potentially life-threatening situation such as chest infection, sepsis, acute heart failure, repeated seizures, or acute kidney failure.
C. *Elective* decision, in a potentially life-altering situation. This encompasses a wide range of situations where someone develops symptoms or signs, usually unrelated to the underlying condition, that potentially indicate a new illness needing investigation and/or treatment. This might include symptoms of cancer, liver disease, or any other of very many diseases.
D. *Elective* decision, concerning screening or preventative interventions. This covers matters such as screening for bowel cancer, influenza vaccination, and especially ongoing treatments such as antihypertensive or anticoagulant drugs.
E. *Elective* decision, concerning ongoing active treatments keeping a disease or other problem under control such as renal dialysis, gastrostomy feeding, insulin, a tracheostomy, ventilation and steroid replacement therapy.
F. *Elective* decision, concerning some specific action that may have lifelong consequences, such as moving to a nursing home.

It is relatively easy to see how the Act applies to single elective decisions with significant consequences (E and F). It is more difficult to apply it directly to a multitude of decisions which have equally or more significant consequences.

A similar problem, making multiple decisions, faces people who have capacity but may lose it. The solution can be an Advance Decision or can be in various, non-legally binding, forms of Advance Care Planning[45–47] (sometimes enacted through the ReSPECT process),[48,49] which set out a decision-making framework that can guide clinicians in any likely situation. The Best Interests process should be used in the same way as Advance Care Planning when making decisions for people lacking capacity. The healthcare team should set out a strategic policy and framework[42] for decisions, based on an understanding of the patient's best interests. This policy should then be used for most if not all decisions until or unless there is a change requiring re-evaluation.

Decisions made and policies set out at a best interests meeting will need to be reviewed. For people whose situation (medically, socially, developmentally, etc.) is stable, then every 6–12 months seems reasonable.[11] A review should always be held when there is a significant change in the situation, or if any person with an interest requests it; this includes carers, commissioners, family members and others. When someone moves to a completely new setting, the new team should hold a new meeting within 7–14 days, using the existing strategy until reviewed.

Undertaking the best interests process

This second half of the article considers how significant healthcare decisions can be made using the best interests process that has been discussed above. This section covers the range of possible decisions, including those relating to life-sustaining treatments, but it is applicable to all other significant decisions. The supplementary data gives aide memoires to support anyone running or participating in a meeting, covering preparation (Table 1) and the meeting (Table 2).

Although this section focuses on a best interests meeting, making decisions in someone's best interests really requires a *process* that encompasses both preparatory work (e.g. collecting and collating information) and actions after the meeting, often including further reviews or meetings.

Initiating the process – recognizing need

The starting point must be to recognize when someone lacks the capacity to make complex healthcare decisions. This is covered in the companion article.[10] If someone lacks capacity, it is usually possible to triage a person into one of four groups:

A. Definitely lack capacity, are unlikely to recover it soon, and need or will need significant decisions made (including people who never developed capacity);
B. Are lacking capacity, but:
    a. no significant (irreversible and/or risky) immediate decisions are needed, and
    b. capacity is likely to be regained before any significant decisions are needed;
C. Definitely have sufficient capacity to make all necessary decisions
    a. some patients will need extra time and help;
D. Very uncertain whether they have capacity and needs a significant decision to be made.
    a. This will include people who have fluctuating capacity

Patients in Group C simply need to be given more time by and support from the clinical team to make an informed decision. Support is not always given,[8] but it is a legal requirement. Patients in Group D will need further assessment, usually by all those involved, and will usually need a meeting both to decide about capacity and to plan further management;[50] if there is an attorney or deputy, they should be involved, as should family and friends.

For patients in Groups A and B, if there is a valid and applicable Advance Decision or an appointed attorney or deputy with the relevant powers in place, then the healthcare team needs to adhere to the Advance Decision or to ask the deputy or attorney to act as decision-maker; if the deputy or attorney does not wish to act as decision-maker, decision-making will revert to the doctor with overall responsibility for the patient's care.

For other patients in Group B, it is unlikely that a meeting will be needed. The clinical team should document both the absence of capacity and any decisions reached, with reasons. If circumstances change, or the loss lasts more than about two or three days, then the healthcare team should start the process of arranging a best interests meeting.

For all patients in Group A, if no valid and applicable Advance Decision exists, the clinical team must undertake a best interests meeting as soon as possible.

The clinical service must also always hold a best interests meeting in the following instances:

- When starting, continuing or stopping treatments (including programmes of treatment) that may save or prolong a person's life;
- Undertaking an investigation and/or treatment and/or programme of management where there is significant risk and/or limited likely benefit or it has potential long-term implications for the patient;
- Moving someone to a different care setting;

- There is disagreement about a decision between different people involved (especially but not only between the healthcare team and family);
- Major uncertainty exists concerning facts such as the patient's wishes, the relevant prognosis, or the intervention options and their risks and benefits.

Preparation – information about the person

As soon as a person is known to lack capacity one must establish whether there is an Advance Decision, or an appointed attorney (or deputy).

In the absence of any legally determined decision or decision-maker, the clinical team must start collecting and documenting information about the patient's disposition towards health decisions as soon as possible. The team should ask about any Advance Statement or Advance Care Plan, because they will be strong evidence to guide the best interests decision-making process. In addition clinicians should ask about healthcare decisions the patients has made or passed an opinion on in the past, and how and on what basis, and their wishes, values, beliefs and feelings. The team should ask about any other factors the person would have considered important when making a decision; this covers a wide range (see pages 63–64 of ref. 11) and it is important to document any evidence or examples.

Healthcare team members should use a variety of methods to elicit information. It is usual to ask if the person ever expressed any opinions relevant to their situation, even if not documented. It is helpful to go through their medical history and family history, to elicit their approach. Inquiries should extend to many other areas, establishing what was important to them. This may include constructing a narrative of their life; what sort of life did they live? This information will accumulate over time, with different people within the healthcare team garnering different information. If an informant expresses an opinion about what the patient would have decided, ask them to explain why they believe this to be the case; this will give information on factors of importance and on decision style.

The primary sources of information will be family and friends who are unlikely to be aware of 'best interests' as defined by the MCA. Consequently, the team should offer informants support and guidance through the whole process. This needs to cover the nature of the information needed, how to give it and their roles, stressing that they are not responsible for making any decisions, and indeed cannot make any decisions. Information for families is available,[51,52] but it is specifically concerned with decisions about gastrostomy feeding. Family members and others who care for the patient or are interested in the patient's welfare will need much support both emotionally and in terms of explanation,[53] including accurate information about the patient's clinical state and prognosis (unless the patient has made a statement denying access in this situation).

The whole clinical team should be involved in collecting information, and should:

- Look for and accept information from anyone who is able to contribute relevant information, not simply family members (e.g. long-standing work colleagues);
  - Always ensure that anyone with different opinions is contacted
  - As far as possible, evidence to support any opinions should be sought
- Accept any information and evidence available, such as audiotapes, emails, and videos;
  - This may include telephone calls from people unable to visit.
- Try to elicit how and why a patient made any relevant decision or would have made a suggested decision
- Make and keep records of all information provided, preferably in a single, shared location.

Further advice is available in Appendix 1 of the recent British Medical Association (BMA) guidance.[11]

If the person has no advocate (i.e. family or other person who knows him or her well enough to give information), then an Independent Mental Capacity Advocate (IMCA) must be appointed whenever a decision is to be made about serious medical treatments, or about transfer to accommodation funded by

the National Health Service (NHS) or local authority.[54,55] They should also be appointed when it is considered inappropriate to consult available advocates (e.g. family) for any reason, for example, if advocates are considered *not* to be acting in the person's best interests. Sometimes, they may be used when there is major disagreement between advocates. This person will try to collect as much information as possible, and represents the patient as far as is possible.

Preparation – clinical information

The clinical information needed to come to a decision in someone's best interests usually covers the following:

- The neurological state:
  - The diagnosis, its past treatment, future treatment options, and prognosis
  - Including a list of all medication
- The current situation in terms of the patient's functional abilities, personal experience, emotional experience, social interaction and quality of life;
- The person's likely functioning, experiences, emotions, social interaction and placement in the future, which should be between 3 and at most 12 months away;
- Details about any treatments or other actions that might be discussed or needed, such as palliative care if gastrostomy hydration and feeding is withdrawn.[11]

A second opinion on the clinical information may be needed. The General Medical Council[56] set out a range of circumstances when a second opinion should usually be sought (para 27) including specifically if clinically assisted nutrition and hydration is to be withdrawn (paras 119–122). Often the person will have been seen earlier by specialists and if this is so, then a second opinion will already exist. If not, or if the clinical situation has changed, a second opinion should be sought if the lead clinician lacks sufficient knowledge about the underlying disease.

Guidance specific to the withdrawal of nutrition and hydration (but not of any other life-sustaining treatment) is available.[11] The role of this doctor is set out thus:

> The second-opinion clinician should assess the case objectively, taking particular care to consider the issue from the patient's perspective. They should take whatever steps they consider necessary to make a judgement as to whether the decision to withdraw (or not to start) CANH is in the best interests of the patient.

It is important to ensure that family and friends are aware of as much of this information as possible before the meeting, because time will be limited and should be used to review and discuss the decisions. No facts presented at the meeting should be a surprise to anyone attending.

Preparation – organization

When organizing any best interests meeting, it is important to ensure that the following will attend, usually in person if possible:

- Family members and friends; for this group it is reasonable to allow people to represent others and/or to encourage submission of written statements (but they do not need to follow any specific format) and/or to join by phone or video-link.
  - They must be given as much information as possible before the meeting, because time will be limited and should be used to review and discuss the decisions.
- Any attorney, deputy or independent mental capacity advocate (IMCA) involved, and
  - Any person named by the patient prior to the loss of capacity as someone to be consulted.
- A senior clinician from the treating team with responsibility for making decision, usually the doctor.
- Other members of the healthcare team involved, especially if they know the person well.
- Other experts, if necessary, to cover
  - The neurological aspects of the illness and/or
  - One or more of any specialists who might advise on one or more of the management options (e.g. palliative care).

Three important matters must be remembered. This is a meeting between clinicians and the patient's family and friends, part of the process of legitimizing clinical decisions; it is not a legal meeting requiring lawyers to be present. Second, as far as is practical, everyone should have as much information as possible before the meeting; no facts presented should be a surprise to anyone. Last, many clinicians and healthcare teams are unfamiliar with the process and find it stressful and confusing; it is well worth obtaining support from someone with appropriate experience and expertise – if necessary, from another organization.

The meeting – preliminary considerations

In urgent situations the initial meeting will focus on the urgent decision and may not be able to follow the detailed guidance given here; nevertheless, it should follow the general principles as closely as possible. Otherwise, a full meeting as described below should be arranged within two weeks of a person losing capacity, if the loss of capacity was due to an acute problem, and within four weeks if it is part of a progressive illness or follows an initial urgent meeting.

There are both costs and benefits associated with holding meetings about patients. The costs are obvious: the time involved, the number of staff and family members involved, and the time that (should be) involved in setting up and documenting the meeting. There are also benefits, and for this group of patients they include the following:

- Collecting and sharing information from a range of different people
  - This should ensure a more informed, coordinated and goal-directed approach to care.
- Discussing the long-term prognosis and possible future options.
- Identifying decisions that need to be made both immediately and in future.
- Making decisions about:
  - Any specific, current problems,
  - A policy to guide future decisions,
  - Whether current active treatments should be continued.

Most of these benefits will improve the quality of care both at the time and also in the longer term, but the benefits depend crucially upon full, accessible and shared documentation of the meeting. With good recording, the meeting will be cost-effective; failure to produce a good record wastes most of the resource devoted to the meeting.

Within the meeting there are important roles to be filled, and it is best to consider beforehand who will act in those roles. The roles include the following:

- A chairperson, who needs to be experienced and good at running meetings of this nature;
- A decision-maker, who is ultimately responsible for making or confirming any decision
  - Attorney or Deputy if appointed; otherwise usually doctor responsible for care
  - Someone to takes notes and prepare a record of the meeting.

Section 2.3 of the BMA guidance[11] discusses the choice of decision-maker in more detail.

There is debate about several matters: whether the chair should be the decision-maker; whether the decision-maker should be allowed to have a competing interest in the decision; what the role of experts attending should be; whether professionals who have strong personal ethical views can attend and so on. The law does not give any specific rule, and there is no definite answer. It is best to allow the group to come to a sensible decision based on the circumstances; any decisions should be recorded and justified in the record of the meeting. Guidance is available, if needed.[2,11,55,56]

The meeting – process

This section gives guidance primarily for healthcare contexts, and considers the meeting as a clinical meeting to set out a policy which will often include discussions about the limits of treatment, and may include not starting, or stopping life-sustaining treatments including, but not limited to, clinically assisted nutrition and hydration. Additional guidance, including an outline agenda, is shown in the Appendix.

Two important preliminaries need to be covered at the start of the meeting, after introductions and an explanation of the purpose and structure of the meeting. First, that the goal is to establish the decisions the patient would have made, based on the clinical facts and using the information garnered from family and friends.

Second, because many people have pre-existing views which may colour their input,[57] professionals attending should be reminded the following:

1. The decisions being discussed are all within the law, and therefore must be considered
2. Professionals must provide relevant information whatever their views but
3. If they hold strong views, they should let the meeting know and
4. They will not be asked to be part of any treatment which they could not deliver for reasons of personal conscience. (This is subject to debate[58–60] but is a practical approach.)

The position of professionals (and organizations) with conscientious objections to a potential decision is discussed further in the recent BMA guidance.[11]

Table 1 (supplementary material) gives details of what needs to be covered; it is comprehensive, showing everything that needs consideration, but only a few parts are likely to require much time except in the first meeting. Nonetheless, certain points must always be covered and recorded, even though they will often be obvious to all concerned:

- Agreement:
  - That there is no valid and applicable Advance Decision
  - On the purpose of the meeting
  - That all necessary people are present (including any advocate) – or have been able to Contribute in the way preferred (e.g. video-link or letter)
  - On who will chair the meeting, and
  - On who is the decision-maker.
- Establishing that the person lacks capacity, agreeing:
  - The nature of the underlying disorder
  - That the person fails one or more tests given in the MCA 2005 (or similar in other jurisdictions)
  - That capacity will not be (re)gained before the decision is needed.

It is then important to review the clinical situation, the prognosis and the treatment options. This may be a brief series of statements, if everyone already knows, or may require considerable time. Both the current situation and the prognosis must be described in terms of functional activities, social interaction, communication and the patient's experiences of pain, distress, pleasure and happiness. Furthermore, any uncertainty must be acknowledged, and reported in terms of upper and lower limits of uncertainty, and the most likely situation. All this information must be documented. The treatment options should only include those considered clinically acceptable; just as a person with capacity cannot insist on a treatment that the doctors do not consider appropriate, so a best interests meeting can only discuss clinically appropriate treatments.

The structure of the meeting after these preliminaries should be tailored to the situation, but there should be a structure. One option is to start considering relatively straightforward matters, working on to consider the more difficult issues. This has the advantage that the person's underlying wishes, values, beliefs and feelings are all discussed early, which often makes the final more difficult decisions easier. It may lead to a longer meeting and some decisions may be overtaken by later decisions.

The alternative is to consider the major decisions first, especially if it concerns possibly not starting, or stopping life-sustaining treatment. The advantages are that this allows more time for discussion, and the decision made may make all other decisions redundant. The disadvantage is that it may be quite stressful, and it does not allow people to develop a better understanding of the process, or of other people. The chair should consider the best structure, before the meeting if possible, and should allow discussion if necessary.

For each decision, the factors that need to be considered include the following:

- The person's beliefs, wishes, feelings, values and any other factors they would consider if they were able to do so.
- Their *current* quality of life, best broken down into
  - Personal experiences; pain, distress, pleasure and happiness
  - Functional autonomy; the behaviours and goals within their capacity
  - Social interaction; roles, availability of others to interact with
  - Meaning in life; having future expectations and wishes.
- Their potential future quality of life (as they would see it) judged on same features
  - Including the effect of any possible change in placement.
- The effect of any intervention, or stopping of any intervention, considered in probabilistic terms covering
  - Risks, pain, time taken, distress etc, set against
  - Effect on one or more aspects of quality of life, broken down as above
  - Length of life.

In principle, each decision should be articulated as what the person would decide, were they able to, given the facts about their situation, prognosis and treatment considered at the meeting.

At the end of the meeting it is vital to:

- State explicitly what has been decided, checking that all agree and understand
  - If there was disagreement, then the reasons behind the decision must also be made explicit publicly.
- Either, if there is agreement confirm:
  - What actions will follow, including
  - Who will undertake them, and when by
  - When the next meeting will be specifying
- Either a date, time and place,
- Or an event that will precipitate a meeting
- Or, in the case of disagreement, specify what the next steps will be, usually one or more of:
  - Obtaining further information and/or a further opinion, and/or
  - Involving a mediation expert, and/or
  - Starting the process of involving the Court of Protection.
- Confirm that a documented record will be written and distributed to all present, and agree who else will get a copy.

Discussion

This article has suggested a change of approach to managing patients who lack the mental capacity to make decisions about their healthcare for more than a few days. In place of giving most attention to single 'best interests meetings', it suggests that the whole process of care should revolve around sharing decision-making with family members and friends from the moment that the loss of capacity is recognized. 'Sharing' decision-making is never a reason for a clinician to duck their responsibility for making a clinical decision. The involvement of family members and friends is *not* so that they make the decisions, it is to provide the healthcare team with as much information as possible about the patient so that all decisions reflect, as far as possible, what the patient would have decided.

The article suggests that large formal and lengthy best interests meeting could be relatively rare if properly conducted. An early meeting held once it is clear that someone may have a long-term loss of capacity can cover many important healthcare decisions. This early meeting should set out as much information as is available about factors likely to determine a patient's choices, and should set out a policy covering possible future decisions. This will reduce the need for urgent meetings subsequently, and it should improve patient care. Regular reviews[11] will generally require less resource, unless matters have changed significantly – although decisions to withhold or withdraw life-sustaining treatments will often require a formal meeting.

This approach depends upon healthcare teams accepting the need to involve family and friends from the outset. It also depends upon healthcare managers and systems giving a higher priority to structuring medical records so that information

about a patient's wishes, values, beliefs and feelings can be documented, updated easily by anyone, and can be accessed quickly and easily when needed to inform a new decision.

Although it has been implicitly concerned more with people with acute-onset conditions, with serious medical decisions, and with people with a prolonged disorder of consciousness, the principles apply generally regardless of cause, prognosis or decision.

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ORCID iD

Derick T Wade https://orcid.org/0000-0002-1188-8442

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