Consultation: Informed Consent and Best Interest Decisions

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Provision of Medical Treatment

- Only lawful if have capacitated consent or acts done in accordance with MCA.
- To deny treatment to an incapacitated patient (P) may breach of statutory duty of care, HRA and Equality Act 2010 and be negligent.
  - *Burke v GMC* [2005] No professional can be ordered to provide medical intervention which, in their view, is not appropriate. No absolute duty to keep people alive, even if possible to do so.
  - *Trust A and Trust B v H (an Adult Patient)* [2006] Art 2 ECHR imposes positive duties but not absolute obligation to give life sustaining treatment where responsible medical opinion supports this. BI not restricted to medical opinion but also social, emotional and welfare considerations.
- So the ‘decision maker’ must assess capacity, if reasonably believe P is incapacitated, act in their best interests and not contrary to the lawful decision of an LPA/deputy or a valid and applicable ADRT.
  - Where treatment is in P’s best interest, if restraint or DOL is required those additional requirements must be met for provision to be lawful.
  - If involves ‘serious medical treatment’ must refer to Court of Protection, likely be reserved to the CoP President/High Court judge.

Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR)

“Every decision about whether or not a person should receive CPR must be made after careful assessment of each individual’s situation. This should be done in consultation with the person and, if the person agrees, their family. It should never be applied to groups of people.”

CQC report: Protect, respect, connect – decisions about living and dying well during COVID-19

- Considering explicitly, and where possible making anticipatory decisions about, whether or not to attempt CPR is an important part of good-quality care for anyone approaching the end of life and/or is at risk of cardiorespiratory arrest.
- If a patient with capacity refuses CPR, or a patient lacking capacity has a valid and applicable ADRT, specifically refusing CPR, this must be respected.
- If the healthcare team is as certain as it can be that a person is dying as an inevitable result of underlying disease or a catastrophic health event, and CPR would not re-start the heart and breathing for a sustained period, CPR should not be attempted. The patient and those close to the patient do not have a right to demand treatment that is clinically inappropriate.
- Even when CPR has no realistic prospect of success, there must be a presumption in favour of explaining the need and basis for a DNACPR decision to a patient, or to those close to a patient who lacks capacity. Consent is not required, but good communication is essential.
- A best interests decision about CPR is unique to each person and is to be guided by the quality of future life that the person themselves would regard as acceptable.
- When done well, DNACPR decisions are made with full involvement of the person, their family and/or carer, and take account of people’s individual needs and circumstances.
Increase in DNACPR decisions during the pandemic

CQC report: Protect, respect, connect – decisions about living and dying well during COVID-1

Messages from the CGC report: Protect, respect, connect – decisions about living and dying well during COVID-1

- People must always be at the centre of their care, including advance care planning and DNACPR decisions.
- Everyone needs to have access to equal and non-discriminatory personalised support around DNACPR decisions, that supports their human rights.
- Clinicians, professionals and workers must have the knowledge, skills and confidence to speak with people about, and support them in, making DNACPR decisions.
- People, their families and/or representatives, clinicians, professionals and workers need to be supported so that they understand what good practice looks like and all share the same understanding and expectations for DNACPR decisions.
- People need to have more positive and seamless experiences of care, including DNACPR decisions, when moving around the health and care system.
- There must be comprehensive records of conversations with, and decisions agreed with, people, their families and/or representatives that support them to move around the system well.
- Health and social care providers must ensure that all workers understand how to speak up, feel confident to speak up and are supported and listened to when they speak up.

Advanced Care Planning

Advance care planning provides people with an opportunity to think about what matters most to them and what level of care and treatment they wish to receive. These discussions can take place at any time, and may include details such as:

- where and how they would like to be cared for, for example at home or in a hospital, nursing home or hospice
- how they want any religious or spiritual beliefs to be reflected in their care
- practical issues, for example what will happen to their belongings or who will look after their pets if they become ill
- what healthcare treatments they want, or do not want, as they near the end of their life
- who they want to be with near the end of their life.
Advance Decision to Refuse Treatment (ADRT)

- A person can make a valid and applicable advance decision to decline a certain treatment and even if they later lose capacity, that decision must be respected, as if it were a person with capacity making it.
- Can be made orally or in writing for most treatments.
- Will only apply to life-sustaining treatment, including DNACPR when it is in writing, is signed and witnessed, and contains a statement that it is to apply even where life is at risk.
- Always ask to see a copy of the ADRT, rather than relying on a summary of it.
- Assume the person had capacity at the time they made the ADRT. If in doubt, legal advice should be sought and, if necessary, the Court of Protection may be asked whether the ADRT can be relied upon.

Lasting Power of Attorney (LPA)

- Must be made in writing, witnessed and registered with the Office of the Public Guardian (OPG) while the person has capacity.
- Can appoint a health and welfare deputy, a finance deputy or both.
- A health and welfare LPA will only come into effect once the person has lost the mental capacity to make that particular decision. A finance LPA can take effect immediately, with the individual’s consent.
- Where this includes the power to consent to or refuse life-sustaining treatment, the health and welfare attorney is the lawful decision-maker.
- The attorney must follow the principles of the MCA, including fulfilling the duty to consult with others and can only act in the person’s best interests.
- An attorney cannot be compelled to make a decision and can exempt themselves.
- Practitioners: always ask to see the LPA, check it’s been validated by the OPG and record this on your files.

Conversations about future care and treatment - ReSPECT

ReSPECT is a good example of an advance care planning process that can support everyone to make decisions around their future care and treatment by focusing conversations around people’s wishes and preferences. Discussions between a person and their family, loved ones and health and care professionals ensures everyone understands what matters to the person and what treatment is realistic.

The ReSPECT process:
1. Discuss and reach a shared understanding of the person’s current state of health and how it may change in the foreseeable future.
2. Identify the person’s preferences for and goals of care in the event of a future emergency.
3. Use that to record an agreed focus of care (either more towards life-sustaining treatments or more towards prioritising comfort over efforts to sustain life).
4. Make and record shared decisions about specific types of care and realistic treatment that they would want considered, or that they would not want, and explaining sensitively advance decisions about treatments that clearly would not work in their situation.
5. Make and record a shared decision about whether or not CPR is recommended.

The ReSPECT form should be kept in an accessible place known to family and carers so that this can be given to ambulance/medical staff and a copy kept on the person’s GP records.
Overarching legal principles

Human Rights Act 1998:
- Article 2: Right to life – includes a duty on public bodies to prevent avoidable deaths
- Article 3: Freedom from torture and inhuman or degrading treatment
- Article 5: Right to liberty and security
- Article 6: Right to a fair trial
- Article 8: Respect for your private and family life, home and correspondence

Equality Act 2010, s149
- (a) eliminate discrimination, harassment, victimisation and any other conduct that is prohibited by or under the Equality Act 2010;
- (b) advance equality of opportunity between persons who share a relevant protected characteristic and persons who do not share it;
- (c) foster good relations between persons who share a relevant protected characteristic and persons who do not share it.

Protected characteristics include age, disability, religion and belief

Informed Consent

For consent to be valid, it must be:
- voluntary – the decision to either consent or not to consent to treatment must be made by the person, and must not be influenced by pressure from medical staff, friends or family
- informed – the person must be given all of the information in a way they can understand about what the treatment involves, including the benefits and risks, whether there are reasonable alternative treatments, and what will happen if treatment does not go ahead
- given with capacity – the person must be capable of giving consent, which means they understand the information given to them and can use it to make an informed decision

If someone over the age of 16 has the capacity to make a voluntary and informed decision to consent to or refuse a particular treatment, their decision must be respected, even if that will result in their death.

If a child under the age of 16 is believed to have enough intelligence, competence and understanding to fully appreciate what’s involved in their treatment, they are “Gillick competent” and can consent to their own treatment.

Otherwise, someone with parental responsibility may need to give consent for a child up to the age of 16 to have treatment.

Mental Capacity Act 2005

"...The healthy and moral human instinct to protect vulnerable people from unwise, indeed, potentially catastrophic decisions must never be permitted to eclipse their fundamental right to take their own decisions where they have the capacity to do so. Misguided paternalism has no place in the Court of Protection."

LB Tower Hamlets v PB [2020] EWCOP34

- 5 key principles in relation to the Mental Capacity Act;
  - A person is assumed to have capacity unless it is established that they do not.
  - A person is not to be treated as unable to make a decision unless all practicable steps to help have been taken without success.
  - A person is not to be treated as unable to make a decision merely because they have made an unwise decision.
  - An act done or decision made under this Act for or on behalf of an incapacitated person must be done or made in his best interests.
  - The least restrictive option should be considered.

- Assumption that those over 16 years old do have capacity (even if they might make bad decisions)
- Capacity relates to ability to make a specific decision, not just a generic statement
- Capacity can change over time, or depending on circumstances (eg when under the influence of substances)
- Can apply to the Court of Protection for orders to take over welfare/financial decisions generally, or to allow/prevent specific steps
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.

- **Stage one** - An impairment of, or a disturbance in the functioning of, the mind or brain, whether permanent (e.g., dementia or a learning disability) or temporary (e.g., substance use or concussion).
- **Stage two** - A person is unable to make a decision for himself if he is unable –
  - to understand the relevant information,
  - to retain that information,
  - to use or weigh that information as part of the process of making the decision, or
  - to communicate his decision.

### Fluctuating Capacity

A 63 year old woman with a diagnosis of personality disorder and poorly controlled diabetes, with fluctuating capacity to take decisions due to variations in blood glucose. The LA sought to move her to a care home, which she strongly opposed. Cohen J rejected that questions of capacity have to be made prospectively in order that professionals responsible for P’s care are able to make decisions in their best interests without daily capacity assessments. Held:

- an assessment of a person’s capacity must be based on their ability to make a specific decision at the time it needs to be made and not their ability to make decisions in general.
- CDM’s personality aggravated her diabetes as it led to poor diabetic control which in turn led to the making of unwise decisions about her treatment and an inability to cooperate with professionals.

### Making an Application to the Court of Protection

The powers of the Court are to:

- Make declarations about a person’s capacity
- Make decisions regarding the personal welfare or finances of an incapacitated person
- Make decisions regarding serious medical treatment, serious interference with the individual’s rights or ethical dilemmas relating to providing, withdrawing or withholding treatment to an incapacitated person
- Resolve disputes – whether within the clinical team, within a family, or between the clinical team and those close to the patient – about what is in the best interests of a person.
- Authorise a deprivation of liberty that cannot be dealt with under the DoLS regime
- Make decisions about an EPA or LPA, such as considering its validity or scope
The Court of Protection (CoP) can appoint a deputy to make welfare and healthcare decisions for someone who lacks capacity.

- The decision to appoint (and who to appoint) must be taken in the best interests of the person, taking into account their wishes and feelings.
- Deputies can only make those decisions that they are authorised to make by the order of the court, and they cannot consent to or refuse life-sustaining treatment.
- The deputy must follow the principles of the MCA, including fulfilling the duty to consult with others and can only act in the person’s best interests.
- The OPG supervises deputies and can investigate concerns.
- Practitioners: always ask to see the court order and record this on your files.

Checklist:

- Is there a valid ADRT? Comply with the ARDT
- Is there a health and welfare attorney or deputy? If so, they are the decision-maker
- Does the CoP need to decide the case? Make an application
- If none of the above apply, follow the clinician-led best interest making process

Treatment must be reasonable, necessary and proportionate, in light of the gravity of the decision and the circumstances in which it is being taken eg there may not be time to properly consult family during an emergency in A&E.

- The decision-maker cannot compel clinicians to provide treatment that would not be available to a person with capacity, nor to perform CPR if the lead clinician deems this is not in the person’s best interest.

Best Interests

- A conclusion that a person lacks decision-making capacity is not an ‘off switch’ for his rights and freedoms. To state the obvious, the wishes, feelings, beliefs and values of people with a mental disability are as important to them as they are to anyone else, and may even be more important. It would be wrong in principle to apply any automatic discount to that point of view. Wye Valley NHS Trust v Mr B [2015] EWCOP 60

- Best Interests are not defined in the MCA, rather it sets out a checklist of factors to be considered when making a best interests decision.
- Not just medical best interest, but rather the person’s welfare in the widest possible sense, and consider the individual’s broader wishes and feelings, and values and beliefs.
- All decisions should follow careful consideration of the individual circumstances of the person and focus on reaching the decision that is right for that person – not what is best for those around them, or what the “reasonable person” would want.
- The person who lacks capacity to make a decision should still be involved in the decision-making process as far as is possible - take all reasonable steps to encourage the person to participate in the decision.
- Take account of the person’s past and present wishes, feelings, values and beliefs where those are known or can be reasonably ascertained.
- Those involved in caring for the person, or interested in his or her welfare, must be consulted about their views on the person’s best interests, and the person’s past and present wishes, feelings, beliefs and values.
- What will be required of a best interests assessment process will depend upon what is reasonable, practical, and appropriate in each case.
- Be clear about what decision is to be taken – eg a decision to withhold futile treatment, not a decision that the person should die.
• Avoid discrimination: You must avoid making assumptions about someone’s best interests on the basis of their age, appearance, clinical condition, or some other aspect of their behaviour.

• Relevant circumstances: You must try to identify all the things the person would take into account if they were able to make the decision themselves.

• Assess whether the person is likely to regain capacity: If they will, can the decision wait until then? This should not be used as a reason to avoid making a potentially difficult or complex decision, but must be based on consideration of individual circumstances.

• Encourage patient participation: Wherever possible, the person who lacks capacity should still be involved in the decision-making process. You must take all reasonable steps to permit and encourage the person to participate in the decision – including using all practical means to improve their ability to do so.

• Life-sustaining treatment: If the decision involves life sustaining treatment, you must not be motivated by the desire to bring about the person’s death.

• Find out the person’s views: You must try to find out what the person’s views and wishes on their situation might be.

• Consult others: If it is practical and appropriate to do so, you must consult other people to find out whether they have any information about the person’s views or wishes.

The Court held that in considering best interests assessments decision-makers must:

“look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude to the treatment is or would be likely to be; and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be”.

The decision maker “must take into account, if it is practical and appropriate to consult them, the views of –

(a) anyone named by the person as someone to be consulted on the matter in question or on matters of that kind;

(b) anyone engaged in caring for the person or interested in his welfare;

(c) any donee of a lasting power of attorney granted by the person; and

(d) any deputy appointed for the person by the court, as to what would be in (a) (e) the person’s best interests and, in particular, as to the matters mentioned in subsection”.

If none of these are available and the decision involves serious medical treatment or long-term care, an Independent Mental Capacity Advocate may need to be instructed, to represent the individual’s views.
Consulting the individual

- Allow sufficient time to explain what is happening, why a decision needs to be made, and to hear from the person involved. This may include:
  - use simple language and/or illustrations to help the person understand the decisions and their options
  - break the issue down over several conversations
  - ask the person about the decision when they feel most relaxed and at ease
  - use specialist interpreters or speech and language therapists to aid communication
  - involve trusted family or carers who may be able to help the person indicate a preference between options
  - observe any non-verbal behaviours

Ascertaining wishes and feelings – s5 MCA

The Mental Capacity Act 2005 (MCA) states that the decision-maker must “…consider, so far as is reasonably ascertainable:

(a) the person’s past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),

(b) the beliefs and values that would be likely to influence his decision if he had capacity, and

(c) the other factors that he would be likely to consider if he were able to do so.”

- To draw a full picture, you may need to involve the person, consider what they have written in the past (including records of advance care planning, emails, social media posts etc) and speak to those close to the individual, even if different people take different views

A balance sheet approach

- Consider a balance sheet approach to weigh the merits and risks of each reasonable option
- If it is clear what the individual’s wishes and feelings would have been prior to losing capacity, that is likely to be the decision (Salford Royal NHS Foundation Trust v Mrs P [2017] EWCOP 23)
- A Best Interest meeting, involving clinicians, family, other professionals involved and carers may help to explore the evidence – it is important to be clear who the decision-maker is at the meeting
- Carefully record that a Best Interest decision has been taken, including:
  - how the decision about best interests was reached
  - what the reasons for reaching the decision were
  - who was consulted to help work out best interests
  - what particular factors were taken into account
- Keep the decision under review
There is a strong legal presumption in favour of prolonging life (Article 2), and decisionmakers must start from this premise, unless:

- there is clear evidence that the person would not want the treatment in question in the particular circumstances
- the treatment itself would be overly burdensome or painful for the person
- there is no prospect that the treatment would return the person to a quality of life that would be acceptable to them

- If the LPA attorney or court appointed deputy is not acting in the person's best interest, a s42 safeguarding referral should be made and this should be reported to the Office of the Public Guardian.
- It may be inappropriate to consult with family member or friends about whom there are concerns about, or proved incidences of, abuse or coercion, or a record should be kept of the reasons their views have been given particular weight.
- Barnet SAB Safeguarding Adult Review – Gabrielle
  - Professionals believed an LPA was in place but no one asked to see the document and Gabrielle’s husband was used as a translator during all conversations
  - Family stopped district nurses and carers visiting during the first lockdown, without a Best Interest decision recorded
  - Low level safeguarding concerns (that did not reach a s42 threshold), including poor hygiene, inappropriate handling and non-compliance with advice on pressure ulcer care were not communicated between agencies or analysed in the context of suspension of health and care support

- Analysis of Safeguarding Adult Reviews commissioned by the LGA and ADASS of 231 SARs nationally
- Mental capacity was the most prevalent theme identified in respect of direct practice:
  - 32 cases identified good practice
  - 138 identified poor practice
- Good practice identified:
  - Capacity (including fluctuating capacity) considered at appropriate decision points
  - An ‘asset-based’ approach taken
  - Robust best interests decisions, including the need for DoLS to be applied, and that outcomes were clearly recorded.
  - Taking a joint approach (the adult social care decision maker taking advice from a specialist health practitioner),
  - Evidence of detailed discussions with the individual
  - Assessment record clearly mapped against the MCA requirements and the guidance of the Code of Practice.
  - Fine-tuning was applied to decisions of differing levels of complexity
Further information is available at:

- Guidance overview: Mental Capacity Act Code of Practice - GOV.UK (www.gov.uk)
- bma-decisions-relating-to-cpr-2016.pdf
- ReSPECT | Resuscitation Council UK
- Analysis of Safeguarding Adult Reviews, April 2017 – March 2019 (local.gov.uk)