

A Focus on Consent and Capacity

The logo for Share2 Care, featuring a large, stylized gear shape in a vibrant pink color. The text 'Share2 Care' is written in white, bold, sans-serif font inside the gear.

**Share2
Care**



Why is consent and capacity an important topic?

It is a general legal and ethical principle that valid consent must be given before any type of medical treatment, examination or personal care is carried out. In other words, the person receiving the care gives their permission before they receive it.

Consent from a patient is needed regardless of the procedure, whether it is an operation, which requires written confirmation of consent, or an every day procedure like taking a patient's temperature or blood pressure, for which verbal consent is sufficient.

Getting consent right is an essential part of healthcare and embodies the values we hold at ELHT. Our core values place importance on **respecting the individual** and **acting with integrity**. When caring for our patients, making sure we get consent right means we can fulfil these values. We can maintain a patient's dignity by allowing them to have control over decisions made regarding their health. We should always view the patient as a partner in their own healthcare.

Not only does this guarantee the dignity of our patients but it also makes patients feel safe in the knowledge that nothing will be done to them without their saying so.

All this contributes to the **quality** of the care we provide at ELHT, which is always **safe, personal and effective**.

Valid Consent

Patients must provide their consent, either written or verbal, for any care or treatment health workers provide.

For consent to be valid, it must be **voluntary** and **informed**, and the person consenting must have **capacity** to make the decision.

Voluntary

The decision to either consent or not to consent to treatment must be made by the person themselves or person acting validly on their behalf e.g parent or lasting Power of Attorney, and must not be influenced by pressure from medical staff, family or friends.

Informed

The person must be given all of the information in terms of what the treatment involves, including the benefits and risks, whether there are reasonable alternative treatments and what is likely to happen if the treatment does not go ahead. Consent is not about bombarding patients with information, it is about a dialogue during which the clinician discusses the proposed treatment and any material risks, i.e. risks that a reasonable person in the patient's position would likely attach significance to. Statistics alone will not determine whether a risk is significant for a particular patient; discussion with the patient will.





Capacity

The person must be capable of giving consent, which means they understand the information given to them and they can use it to make an informed decision.

If an adult has the capacity to make a voluntary and informed decision to consent to or refuse a particular treatment, their decision must be respected (see page 4).

However, refused consent offers an opportunity to explore with the patient if there is something worrying or upsetting them. Discussing or resolving another problem will often mean that consent for the procedure is granted.

How is consent given?

If someone is going to have a major medical procedure such as an operation, then consent would need to be confirmed in writing. If it is a planned procedure, then this would ideally be done well in advance so the patient has plenty of time to obtain information about the procedure and ask questions.

If the patient changes their mind at any point before the procedure, they are entitled to withdraw their previous consent.

However, written consent does not need to be obtained for everything that is done for patients

“After being a bag of nerves prior to my appointment, I was greeted by a lovely student nurse who did all my observations beforehand. She took the time to explain the procedure to me, reassured me and was willing to answer any questions I had.”

I was then greeted by the Doctor who would be doing the procedure who himself kindly went through my consent form with me.”

Feedback posted on NHS Choices July 2018

Consent can be given verbally – for example, a patient saying they are happy to have an x-ray.

“The anaesthetist and registrar took time to explain what would be happening, ensuring that I understood and answering any questions. The consultant also stopped by to speak to me which was thoughtful and re-emphasised my view that I was being treated as an individual”

Feedback posted on NHS Choices May 2018



Learning from complaints

The son of an elderly patient raised the issue of how important it is to discuss with the patient every aspect of the care that is being given to them. His mother was put into continence pads without being asked. This was stressful for a patient who wanted to maintain her independence.

Key Learning

The importance of seeking verbal consent from patients for all aspects of care. Remember that consent is the responsibility of **all** members of staff who are involved in the care of a patient.

Think about the dignity of the patient.



Capacity and consent from children and young people

If they are able to, consent is usually given by patients themselves.

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

More information about the rules of consent applying to children and young people can be found here

<https://www.nhs.uk/conditions/consent-to-treatment/children/>



When consent is not needed

There are a few exceptions when treatment may be able to go ahead without the person's consent, even if they are capable of giving their permission.

- The patient requires emergency treatment to save their life, but they are incapacitated (for example, they are unconscious and therefore lack capacity at that point), then immediate and urgent action but this must be in the patient's best interest and it important to ensure all normal requirements are met, e.g. contact with next of kin/LPA ('next of kin' is a point of contact when you are admitted to hospital, that is, a person hospital staff would look to for guidance but who has no legal liabilities, rights to your medical records or personal possessions).
- The patient immediately requires an additional emergency procedure during an operation – there has to be a clear medical reason why it would be unsafe to wait to obtain consent. It can't simply be for convenience of the clinical team or even if the team thinks it will be more convenient for the patient
- The patient has a severe mental health condition, such as schizophrenia, bipolar disorder or dementia, and meets the requirements for compulsory detention and treatment (under the Mental Health Act 1983)
- The patient requires hospital treatment for a severe mental health condition, but self-harmed or attempted suicide while having mental capacity and is refusing treatment (under the Mental Health Act 1983)
- The patient is a risk to public health as a result of highly infectious diseases.



Capacity

Capacity means the ability to use and understand information to make a decision, and communicate your own decisions.

Some patients may lack capacity to consent to care and treatment on either a short term basis, or sometimes permanently.

Examples of how a person's brain or mind may be impaired include:

- mental health conditions – such as schizophrenia or bipolar disorder or dementia
- severe learning disabilities
- brain damage – for example, from a stroke or other brain injury
- physical or mental conditions that cause confusion, drowsiness or a loss of consciousness
- intoxication caused by drug or alcohol misuse.

Someone with such an impairment is thought to be unable to make a decision if they can't:

- understand information about the decision
- remember that information
- use that information to make a decision
- communicate their decision by talking, using sign language or by any other means.

How capacity is assessed

As capacity can sometimes change over time and is specific to individual conditions, it should be assessed each time that consent is required.

Capacity should be assessed by any clinician who is either:

- recommending the treatment or investigation
- involved in carrying it out.

If the health professional feels the patient doesn't currently have the capacity to give consent, decisions will need to be made in the best interests of the patient. Refer to the following page on '**Determining a Person's Best Interest**'. This highlights the importance of involving people close to the patient, in line with the ELHT Mental Capacity Act policy (CO72) and supporting guidelines.

Any decision that supports an individual having been assessed as having or lacking capacity should be fully documented.

Respecting personal beliefs and determining a person's best interests

Respecting personal beliefs

If someone makes a decision about treatment that other people would consider to be irrational, it doesn't necessarily mean they have a lack of capacity, as long as they understand the reality of their situation. Having respect for the dignity and autonomy of the patient is the foundation of consent. It is also important to remember that it is the decision-maker who needs to be satisfied that a patient lacks capacity for that particular decision (or decisions).

For example, a person who refuses to have a blood transfusion because it's against their religious beliefs wouldn't be thought to lack capacity. They still understand the reality of their situation and the consequences of their actions.

But someone with anorexia who is severely malnourished and rejects treatment because they refuse to accept there's anything wrong with them could be considered incapable.

This is because they're regarded as not fully understanding the reality of their situation or their consequences.

Determining a person's best interests

If an adult is assessed as lacking the capacity to give consent, a decision on whether to go ahead with the treatment will need to be made by the health professionals treating them. Clinicians are not consenting to treatment but if the patient lacks capacity, they are carrying out treatment in the patient's best interests, following consultation with relevant interested parties, including relatives. To make a decision, the person's best interests must be considered.

There are many important elements involved in trying to determine a person's best interests.

These include:

- advanced statements
- considering whether it's safe to wait until the person can give consent if it's likely they could regain capacity at a later stage
- involving the person in the decision as much as possible
- trying to identify any issues the person would take into account if they were making the decision themselves, including religious or moral beliefs – these would be based on views the person expressed previously, as well as any insight close relatives or friends can offer.

If a person is felt to lack capacity - AND there is no one suitable to help make decisions about medical treatment, such as family members or friends - an independent mental capacity advocate (IMCA) MUST be contacted to ensure the patient is represented in decision making.

Remember – whilst it is the responsibility of the clinician to make **clinical** decisions in the best interests of the patient, when a person is considered to lack capacity, it is essential where possible to consult with other people close to the person (family and friends) to try and reach a shared agreement about what care and treatment should be provided. The patient's primary contact and family members can help by letting you know what decision they believe the patient would make for themselves if they were able to do so.

Best interest decisions can and should be made by the relevant decision maker following discussion and hopefully agreement with all relevant persons, including family. This highlights the importance of involving people close to the patient, in line with the ELHT Mental Capacity Act policy (CO72) and supporting guidelines. If there is disagreement then it likely that a decision by a court of protection judge might be required.

Changes in capacity

A person's capacity to consent can fluctuate. For example, they may have the capacity to make some decisions but not others, or their capacity may come and go.

In some cases, people can be considered capable of deciding some aspects of their treatment but not others.

For example, a person with severe learning difficulties may be capable of deciding on their day-to-day treatment, but incapable of understanding the complexities of their long-term treatment.

Some people with certain health conditions may have periods when their capacity could change.

For example, a person with schizophrenia may have psychotic episodes (when they can't distinguish between reality and fantasy), during which they may not be capable of making certain decisions.

A person's capacity can also be temporarily affected by:

- shock
- panic
- fatigue (extreme tiredness)
- medication.

Concerned?

If you have any concerns that a case is not being handled in line with these principles, ensure the ELHT Safeguarding Team are contacted.



Consent and life-sustaining treatments

A person may be being kept alive with supportive treatments – such as lung ventilation – without having made an advance decision which outlines the care they would choose to receive.

In cases where patients are being artificially maintained and an Advanced Directive has **not** been made (sometimes known as a 'living will'), then a decision about continuing or stopping treatment should be made based on what that person's best interests are believed to be.

To help reach a decision, the healthcare professionals responsible for the person's care should discuss the issue with the relatives and friends of the person receiving the treatment.

They should consider, among other things:

- what the person's quality of life is likely to be if treatment is continued
- how long the person may live if treatment is continued
- what chance there may be of the person recovering.

Treatment may be withdrawn if there's an agreement that continuing treatment isn't in the person's best interests.

The case can be referred to the Court of Protection before further action is taken if:

- an agreement can't be reached
- a decision is being considered about whether to withdraw treatment from someone who has been in a state of impaired consciousness for a long time (usually at least 12 months).

It's important to note the difference between withdrawing a person's life support and taking a deliberate action to make them die. For example, injecting a lethal drug would be illegal.





Obstetrics: Real-life consent - getting it right

Wrong:

1. The obstetrician routinely provides an Induction of Labour (IOL) leaflet to women nearing their due date stating 'we will organise an induction date for you when you go overdue'
2. This is followed up with the woman being given an IOL date.
3. The woman is told that if she goes overdue 'her baby may die'
4. No further information or alternatives are provided.

Right: (modified from Birthrights)

1. The obstetrician has an initial discussion with the woman in the antenatal clinic about induction of labour if she goes overdue. This discussion is supported with a leaflet on IOL, but the leaflet does not replace the dialogue.
2. At a follow up discussion the doctor takes account of the woman's wishes for the birth and her particular medical (e.g. first time mother) and social situation.
3. The obstetrician explains the risks of exceeding her due date using accurate and comprehensible information that does not put undue pressure on the woman. If statistics are used, these are absolute, not relative figures.
4. She should then be told of 'any material risks' of induction to both herself and her baby. It is obvious that most women would wish to know the likelihood of success and failure of induction in that clinician's experience at the hospital in question, and the risks should induction fail. These will include fetal distress, assisted birth, with consequent potential for perineal trauma, and emergency c-section.
5. The obstetrician should suggest alternative courses of action, including waiting for natural labour to begin and elective c-section.
6. The discussion and its outcome is documented in her antenatal notes.

Advance Decisions and Power of Attorney

If a person knows their capacity to consent may be affected in the future, they can choose to draw up a legally binding advance decision (also known as a living will).

This sets out the procedures and treatments that a person refuses to undergo.

People can also choose to formally arrange for someone, often a close family member, to have **Lasting Power of Attorney (LPA)** if they wish to anticipate their loss of capacity to make important decisions at a later stage. This enables you to give another person the right to make decisions about your care and welfare. This can only be used when capacity is lost.

Someone with an LPA can make decisions on behalf of a patient about their health. This can only be used when capacity is lost, although a person can choose to specify in advance certain treatments they would like them to refuse.

The Mental Capacity Act

The Mental Capacity Act 2005 Code of Practice gives guidance on what healthcare decisions a person appointed as an attorney under an LPA can make.

A personal welfare LPA allows attorneys to make decisions to accept or refuse healthcare or treatment unless the individual has stated clearly in the LPA that they do not want the attorney to make these decisions.

Even where the LPA includes healthcare decisions, attorneys do not have the right to consent to or refuse treatment in situations where:

- the donor has capacity to make the particular healthcare decision (section 11(7)(a)) An attorney has no decision-making power if the donor can make their own treatment decisions
- the donor has made an advance decision to refuse the proposed treatment (section 11(7)(b)) An attorney cannot consent to treatment if the donor has made a valid and applicable advance decision to refuse a specific treatment. But if the donor made an LPA after the advance decision, and gave the attorney the right to consent to or refuse the treatment, the attorney can choose not to follow the advance decisions, as long as they ensure that they are still acting in the patient's best interest.
- a decision relates to life-sustaining treatment (section 11(7)(c)) An attorney has no power to consent to or refuse life-sustaining treatment, unless the LPA document expressly authorises this.
- the donor is detained under the Mental Health Act. An attorney cannot consent to or refuse treatment for a mental disorder for a patient detained under the Mental Health Act 1983.

LPAs cannot give attorneys the power to demand specific forms of medical treatment that healthcare staff do not believe are necessary or appropriate for the donor's particular condition.

Attorneys must always follow the Act's principles and make decisions in the donor's best interests. If healthcare staff disagree with the attorney's assessment of best interests, they should discuss

the case with other medical experts and/or get a formal second opinion. Then they should discuss the matter further with the attorney.

If they cannot settle the disagreement, they can apply to the Court of Protection. While the court is coming to a decision, healthcare staff can give life-sustaining treatment to prolong the donor's life or stop their condition getting worse.

An attorney can only consent to or refuse life-sustaining treatment on behalf of the donor if, when making the LPA, the donor has specifically stated in the LPA document that they want the attorney to have this authority.

As with all decisions, an attorney must act in the donor's best interests when making decisions

about such treatment. This will involve applying the best interests checklist and consulting with carers, family members and others interested in the donor's welfare. In particular, the attorney must not be motivated in any way by the desire to bring about the donor's death. Anyone who doubts that the attorney is acting in the donor's best interests can apply to the Court of Protection for a decision

Copies of LPAs should be requested from relatives and held in the patient's records. Personal health and welfare LPAs can vary in terms of the decisions that the donor has granted authority to be made on their behalf and these should be noted.



Learning from complaints: Barbara and Annie's story...

Having been diagnosed with Alzheimer's disease following a long career as a nursing sister and twenty years as the owner of both a care home and a nursing home, my mum could not hide from the realities of what may lie ahead. I recall her sitting in my lounge explaining her fear that it was not just the terrifying journey she faced towards inevitable death, it was her belief that the NHS and Social Services could "steam roll in and take over a person's life". In order to avoid this happening to her and so that she had some level of control over her destiny, she set about using a powerful area of law known as 'The Mental Capacity Act 2005' to ensure that when she became vulnerable she was enabled to lead as fulfilling and as normal a life as possible and everyone making decisions on her behalf and providing care were legal bound to respect her rights, wishes and decisions.

"I hold a fundamental belief that a person should be treated with grace and dignity and have their wishes and beliefs respected and met wherever possible".

Barbara Taylor

We talked endlessly covering everything we could think of from belief systems, to food choices and personal hygiene. We discussed the care she wanted to receive at the different stages of her Alzheimer's journey; she was very specific about where she did and didn't want to live and that I was to be the only person ever to make such decisions on her behalf. She even decided who her private carer/support worker was to be and the arrangements for her end of life and subsequent funeral.

In order to ensure her wishes were followed I assisted my mum to engage in life story work and create an advance statement and an advance decision to refuse treatment (ADRT). My mum decided to appoint me as her power of attorney for property and finance, health and welfare. This meant that in any instances where she lacked capacity I would become my mum's decision maker and everyone involved in her care would be enabled to utilise this careful planning to gain insight and understanding into who Barbara was as a person, her values, beliefs, wishes and legally binding decisions whenever there was a need to make informed decisions in her best interests.

Tragically my mum's worst fears were to be realised; all her planning and my position as LPA were not respected by many in the NHS. When admitted to hospital after a fall my mum began to rapidly decline, she needed 24 hour nursing care and often lacked mental capacity, so the powerful legal documents she had put in place came into force. As the lawfully appointed

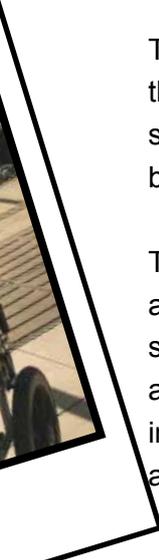




decision maker, I worked with my mum to make plans for her discharge from hospital and future care. This included my arranging a nursing bed in a residential dementia unit in line with my mum's wishes. However I believe others undermined this, our plans were cancelled and my Mum sent to a different place against our express wishes. By profession I am a counsellor/psychotherapist who specialises in working with survivors of trauma and abuse. As a person I hold strong ethical beliefs about what it is to be human and how people should be empowered, self-governing and valued as an individual. Yet despite having promised my mum that I would always act in her best interests my experience was that I was repeatedly prevented from acting ethically in carrying out my duties as her LPA. Whilst progression of her illness meant my mum was changing and losing capacity, she was still a human being and she was still essentially Barbara, just a different and fluctuating version of Barbara. I held witness to the traumatic impact the differing negative events had on both mum and myself and I also saw the positive impact that was gained when my mums rights and wishes were respected.

With help and support from some amazing people my mum was eventually moved to the care home bed I had originally booked for her. The support worker she had chosen to assist her to continue to get out and about and engage wherever possible in her daily routines, interests and activities was engaged. I also worked with others to arrange things such appropriate and respectful incontinence wear, a wheelchair for the times when she was struggling to walk safely and a weekly session with a reflexologist/massage therapist who my mum developed a great relationship with.

Though my mum's health continued to deteriorate as her disease progressed those who knew her saw the immense positive benefits she gained when her wishes were followed. Close friends mentioned how she was "positively thriving" and expressed a belief that if I hadn't fought to achieve this and she had been forced to live the life others had chosen, she would have given up and been dead by now!



There were numerous further incidents where our decisions and rights were disrespected weaving a tragic and devastating thread through our lives for over two years. But there was also a parallel story, a story about what can happen when those providing care work together to value a person as a unique individual and respect their rights, choices and decisions. This is a story about quality of life in Alzheimer's and how the Mental Capacity Act 2005 and those providing care can work together to assist a vulnerable person with capacity issues to live the life they choose and gain positive benefits for themselves as they can live in the knowledge they did it right and made a positive difference!

I believe that the Mental Capacity Act 2005 is a truly amazing and empowering piece of legislation that seeks to ensure that the individual rights and wishes of a person who lacks capacity continue to remain at the heart of all decision making regarding them. Whilst my mum and I were harmed and let down on numerous occasions, we also experienced the positive benefits that are to be gained when people strive for ethical good practice, respect individual rights and the law and provide compassionate care. My hope is that our experiences will be used as a learning tool so that others may benefit from gaining new insights into the reasons and implications of this important area of law.



Key learning

I think that the key learning that comes out of this experience is that;

- Actions and decisions made by those providing care can have significant and even life changing physical and emotional consequences for the person concerned.
- By respecting the law and a person's rights, wishes and decisions we can all work to make a positive difference to the life of someone who needs our help and support.
- It is a legal requirement for everyone involved in a person's care to always act in that person's best interests and so we need to know exactly what the law says best interest's means.
- It is vital for everyone involved in making best interest decisions be they big or small, to understand that this means truly using empathy and available information to discover and make the decision that the person would have made if they were able to do so.
- A capacity assessment should always be undertaken and recorded on the patient's notes where there are concerns about capacity.
- Advance statements are a powerful tool that must always be considered when making decisions. If you disagree with the person's advance statement you must always keep a record of this and be prepared to justify your decision if challenged.
- If a person in your care has created a Lasting Power of Attorney (LPA) for either property and finance or health and welfare, then the attorney will always be the decision maker for all matters within their powers. Healthcare professionals are legally required to ensure they understand and respect the extent of the powers bestowed on the attorney.
- Healthcare professionals need to ensure they flag up any LPA or Advance Decisions on their systems and ensure that they understand and respect them.
- Where a valid and applicable Advance Decisions to Refuse Treatment (ADRT) exists this is a legally binding document and must always be adhered to by anyone providing care.
- A do not resuscitate order is not legally binding and is simply a useful communication tool used by the NHS.

Within ELHT, there is a policy to support you in applying the MCA and best interest decisions. Remember: the Safeguarding Team will support you in this.



Quickfire Learning

“Talk CPR – Discuss DNACPR” Resources

Talk CPR's goal is to encourage conversation about CardioPulmonary Resuscitation (CPR) for people affected by life-limiting and palliative illnesses. Talking about Do Not Attempt CardioPulmonary Resuscitation (DNACPR) is an important part of advance care planning and can help minimise distress at a later stage.

The aim is to create awareness of what CPR and DNACPR advance decisions are, and to point people affected by life-limiting conditions towards resources and information. On the Talk CPR website there are a few videos that explain what CardioPulmonary Resuscitation is, and what it isn't, how successful it is and why some people want to discuss this with their doctor in advance of it becoming necessary.

For more information, please visit <http://talkcpr.wales/>

Royal College of Physicians “Breaking Bad News” e-learning

The Royal College of Physicians have launched an e-learning course entitled “Breaking Bad News”. This course aims to equip the user with skills in breaking bad news to both patients and next of kin. It provides an opportunity to reflect on the challenges and key skills required in these difficult conversations, and highlights physicians' frontline experiences around having honest conversations about dying.

For more information, please visit <https://www.rcplondon.ac.uk/education-practice/courses/breaking-bad-news-guide-doctors>





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