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Capacity and decision making in chronic kidney disease

Patient Information



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Medical professionals should always take into account their patient's wishes when recommending a course of treatment. Sometimes however the patient is not able to express their own wishes due to illness or impaired capacity (ability to make decisions). If a person cannot make decisions for themselves, their relatives or friends should be consulted and may be asked to advise the health care professionals on their likely wishes. In these circumstances, the health care professionals bear the responsibility for the decision-making.

This leaflet describes how capacity is assessed, the role of Lasting Power of Attorney (LPA), the best interests process and how it can apply to patients with Chronic Kidney Disease (CKD).

Note – this information only applies to England and Wales as Scottish laws are different.



What does the law say about capacity?

The Mental Capacity Act is a law aimed at protecting potentially vulnerable people aged 16 years and over who lack the ability to make their own decisions.

The Law is based on five important principles:

- 1.** It is assumed that everyone has capacity unless it can be shown that they do not
- 2.** The individual must be supported to make their own decisions and must be given all appropriate help before anyone concludes that they are unable to do this;
- 3.** The individual has the right to make what might appear to be a strange or unwise decision if they choose to;
- 4.** Best interests - anything done for or on behalf of people without capacity must be in their best interests;
- 5.** Least restrictive intervention - anything done for or on behalf of people without capacity should be the least restrictive of their basic rights and freedoms. The medical team would always want to take account of a patient's wishes and preferences when recommending a course of treatment



How is capacity assessed?

Capacity is assessed based on a person's ability to:

- 1.** Understand information about the decision to be made
- 2.** Remember the information
- 3.** Use or weigh-up the information as part of the decision process
- 4.** Communicate their decision to others

An inability in any of these areas means a person may not have capacity to make a decision. They may be able to make simple decisions about their health, but may not have capacity for more complex decision-making.

When might capacity be lost?

Capacity can be lost due to age-related impairments such as dementia, illness or an accident (such as a head injury). A patient with dementia for example may be deemed to lack capacity to make certain decisions if they cannot remember information related to their health. An inability to make a decision in one area of life (e.g. health) does not mean that the person is completely unable to make decisions for themselves. They may still be able to live independently and manage day-to-day tasks but require help when it comes to some decisions about their health.



How does this affect patients with CKD?

Many patients with CKD are becoming older and frailer. As well as their kidney condition, they can develop illnesses such as dementia and Parkinson's disease, or they may have a stroke, which can all affect their ability to make or express their decisions about their treatment. It may be that the journey to hospital is becoming too much for them or that dialysis itself is frightening or upsetting.

When this occurs it is important that the healthcare team discuss the situation with the patient and assess their capacity to make their own decisions. If they are deemed unable to do this, a decision may need to be taken on the patient's behalf, in consultation with their family members. This may include taking a palliative, comfort-based approach to the patient's care. It may also involve taking an end-of-life care approach, by deciding to stop dialysis if it is felt that this is no longer in the patient's best interests.



How are relatives involved in these decisions?

Before losing capacity the patient may have made a **Lasting Power of Attorney for Health and welfare**. This is a legal document that gives a named person (usually a relative) the right to make decisions about the patient's health if they are no longer in a position to do so themselves. Healthcare professionals are legally required to follow the relative's views as if they were the patients. Patients may also have discussed their wishes and preferences. Although these are not legally binding, they are a useful guide.

Without a Lasting Power of Attorney, the consultant in charge of the patient's care is required to make decisions in the patient's best interests. This should still involve the patient's relatives who can advise the healthcare team about the patient's known or likely wishes, preferences, feelings, beliefs and values. This is not the same as making those decisions. That responsibility ultimately lies with the healthcare team.



What decisions may have to be made at this time?

When a patient is approaching the end of their life, it is vitally important to weigh up the pros and cons of all treatments and only offer those that benefit the patient and focus on their comfort. For example, dialysis can take up many hours in a week and may not be the best use of a patient's limited time left. At this time decisions such as prescribing antibiotics for infections and treatments for symptom management are also considered. A decision to not resuscitate the patient if their heart stops, and therefore allow a natural death, should also be discussed.

What if there is a disagreement over the best course of treatment?

The patient's best interests should always be the main focus when making any decisions on their behalf. If there are disagreements over appropriate medical care, a multi-professional discussion (case conference or best interest meeting) may be held or advice sought from an independent adviser. The hospital's chaplaincy team may be asked to be involved to provide guidance from a faith perspective. Unless treatment is felt to be actively harmful to the patient it will not be stopped until any disagreement is resolved. Any discussions will always take place before a treatment is changed.



Where can I find out more information?

- NHS Choices website: [What is the Mental Capacity Act - www.nhs.uk/conditions/social-care-and-support/mental-capacity](http://www.nhs.uk/conditions/social-care-and-support/mental-capacity)
- NHS Choices website: www.nhs.uk/Planners/end-of-life-care/Pages/What-is-end-of-life-care.aspx
- Kidney Research UK – Dialysis Decision Aid: <https://www.kidneyresearchuk.org/file/health-information/KR-decision-Aid-print-friendly.pdf>
- Kidney Care UK – Choosing to stop dialysis: www.kidneycareuk.org/documents/173/Choosing_to_stop_dialysis.pdf

With thanks to the Renal and Palliative Care teams at the Royal Free Hospital, London



 www.kidneycareuk.org

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