

Capacity and decision making in chronic kidney disease



Working together for better patient information

Your healthcare team should always consider your wishes when recommending treatment for chronic kidney disease (CKD).

There may be situations, such as a serious illness or an injury, where you might not be able to communicate your preferences or make decisions about your own healthcare. This is often referred to as lacking '**capacity**'.



Capacity means the mental and legal ability to make decisions.

It involves:

- understanding the information relevant to your decision
- retaining that information long enough to make your own choices
- weighing the information as part of your decision-making process
- communicating your decision to other people

If you are unable to do these things, it might be said that you lack the capacity to make a particular decision at that time. This can be temporary, for example, if you are unconscious or heavily medicated, or it can be more permanent, due to conditions like dementia. Planning ahead for such circumstances can ensure that your healthcare wishes are known and respected, even when you're not able to communicate them yourself.

If you cannot make healthcare decisions for yourself, your family members or friends may become actively involved in making these decisions on your behalf.

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.

It is based on five 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 given all appropriate help before it is decided 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. Anything done for or on behalf of people without capacity must be in their best interests.
5. The medical team will always take account of a patient's wishes and preferences when recommending a course of treatment.

The Mental Capacity Act covers England and Wales. Similar laws exist in Scotland (**Adults with Incapacity (Scotland) Act**) and Northern Ireland (**Mental Capacity Act (NI)**).



How is capacity assessed?

Capacity is assessed based on your ability to:

1. Understand information about the decision to be made
2. Remember the information
3. Consider the information as part of the decision process
4. Communicate your decision to others

If you are unable to do one or more of these, you may not have capacity to make a decision. You may have capacity to make simple decisions about your health but not have capacity for more complex decision-making.

Why might I lose capacity?

You may lose capacity due to illness or an accident such as a head injury. This may be temporary or permanent.

People with CKD are often older. As well as CKD, other conditions such as dementia, Parkinson's disease or a stroke may affect your ability to make or communicate decisions about your treatment.

For example, if you have dementia, you may lack capacity to make decisions if you cannot remember your health information.



What will happen if I lose capacity?

Your healthcare team should discuss the situation with you and assess your capacity to make your own decisions. If they feel that you can no longer make your own decisions, they should talk to your family and friends to make a decision on your behalf.

If you are unable to make a decision about your health, you may still be able to make other decisions about your life, such as managing everyday tasks.

What healthcare decisions might need to be made?

Capacity is relevant to all healthcare decisions. This can be about your day-to-day care or decisions about supporting your quality of life and reducing any suffering. This might include:

- adjusting the amount of pain medication or antibiotics that you receive
- reducing or stopping dialysis
- deciding if you should be resuscitated if your heart stops beating
- deciding on the location of end-of-life care and death



How can I decide who makes decisions on my behalf?

Before losing the ability to make decisions, you may choose to make 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 your health when you can no longer do this yourself.

Discussing your future healthcare wishes and the possibility of not being able to make your own decisions can be challenging. It may feel uncomfortable to talk about this with family and friends. However, having these conversations can be incredibly valuable and can provide you with peace of mind, knowing that your loved ones understand your preferences and will be able to honour them. It also helps to relieve the burden on the people close to you during what can be an emotionally difficult time, as they can be confident they are making decisions that fit with your values and wishes.

Taking the time to express your intentions clearly through a Lasting Power of Attorney for Health and Welfare, and discussing your wishes with those you trust, ensures that your voice is heard when you may not be able to speak for yourself.

Healthcare professionals are legally required to follow the decisions that the named person makes on your behalf.

Without a Lasting Power of Attorney, your kidney doctor is responsible for making decisions in your best interests. In some cases the medical team may ultimately decide which medical decisions are in your best interests, with input from those with a Power of Attorney.

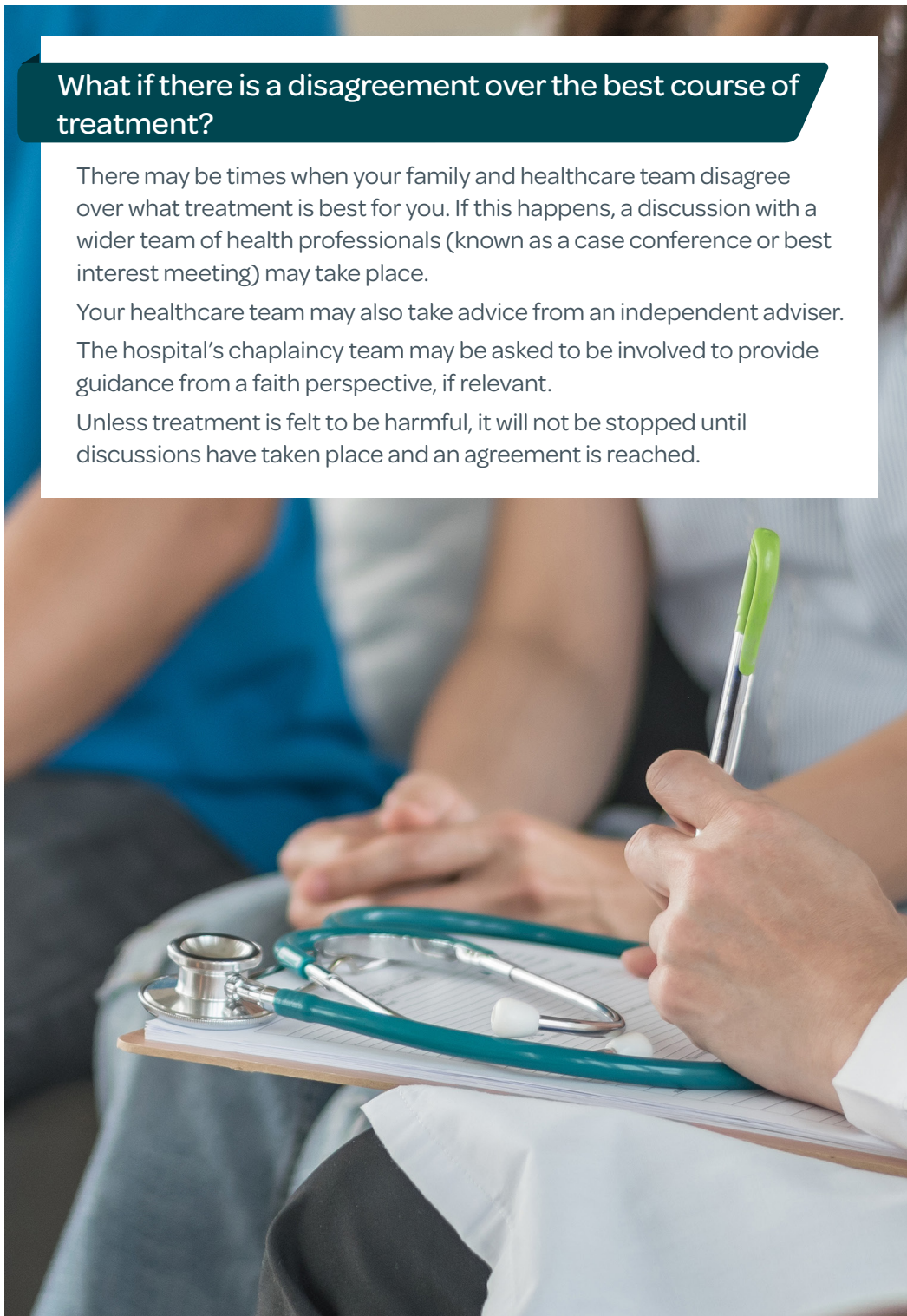
You may have discussed your preferences for treatment and care with your healthcare team, family or friends. Such discussions are useful to allow the healthcare team to understand your wishes, preferences, feelings, beliefs and values. You should keep in mind that these discussions are not legally binding without a Power of Attorney in place and ultimately your healthcare team is responsible for the healthcare decisions.

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

There may be times when your family and healthcare team disagree over what treatment is best for you. If this happens, a discussion with a wider team of health professionals (known as a case conference or best interest meeting) may take place.

Your healthcare team may also take advice from an independent adviser. The hospital's chaplaincy team may be asked to be involved to provide guidance from a faith perspective, if relevant.

Unless treatment is felt to be harmful, it will not be stopped until discussions have taken place and an agreement is reached.



Where can I find out more information?

- **Kidney Care UK** -
www.kidneycareuk.org/kidney-disease-information/treatments
- **NHS Choices** Mental Capacity Act -
www.nhs.uk/conditions/social-care-and-support/mental-capacity
- **NHS Choices** end of life care - www.nhs.uk/conditions/end-of-life-care
- **Dialysis Decision Aid** -
www.kidneyresearchyorkshire.org.uk/yorkshire-dialysis-and-conservative-care-decision-aid

Contact us to see how we can support you

Call free on
0808 801 00 00

(Monday to Friday, 9am-5pm)

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www.kidneycareuk.org



If you have feedback about this leaflet, please let us know at: **feedback@kidneycareuk.org**

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