NHS
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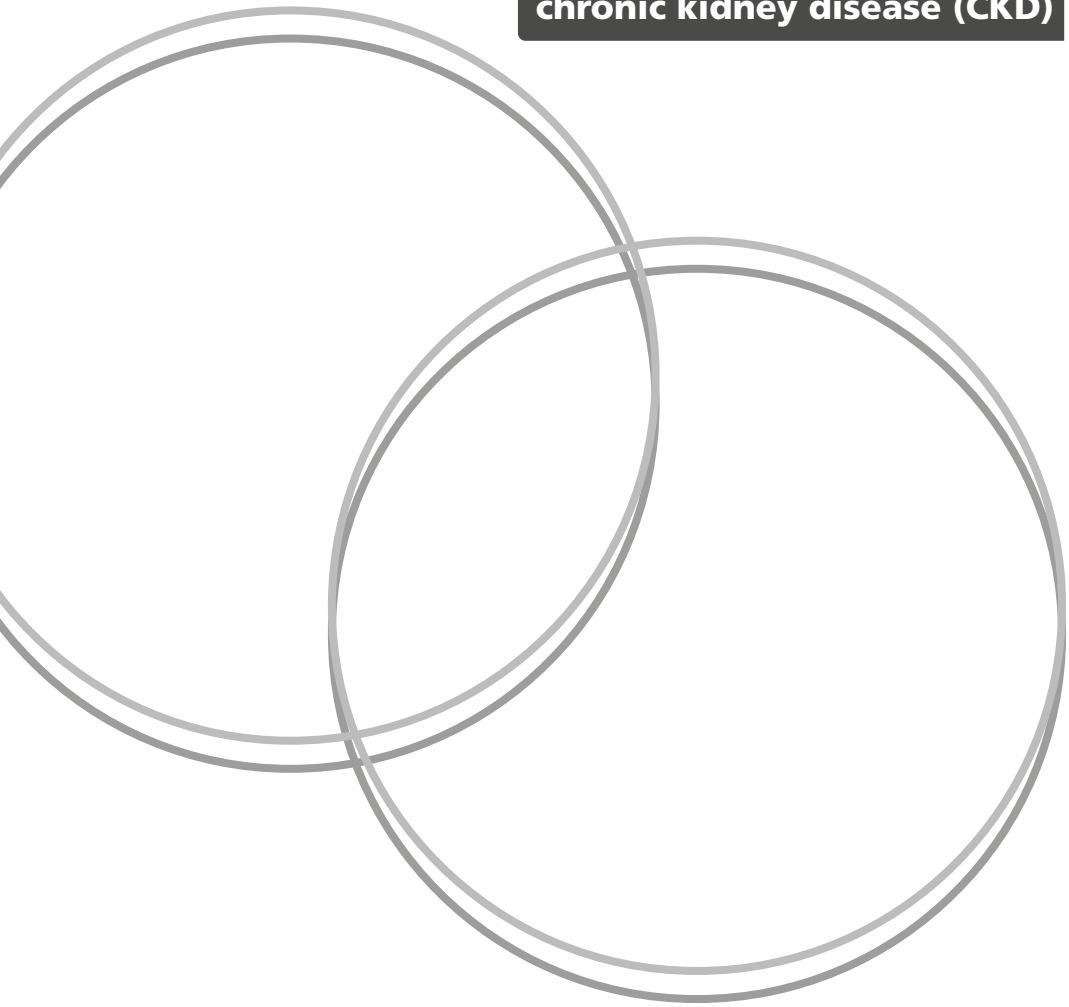
Renal: Looking Ahead, Talking About Your Future Care

Information for people with chronic kidney disease (CKD)



You have been given this leaflet because we would like to know what your thoughts are about your care in the future. Talking about your future with your loved ones and health care team helps us to know what your wishes are and how we can support you.

This process can lead to you making an Advance Care Plan (ACP).

What is an Advance Care Plan (ACP)?

An ACP is part of a process that involves talking and documenting about what is important to you. It helps your family and health care professionals understand what you do and do not want to happen to you should you become seriously ill and not in a position to make decisions for yourself.

Having conversations about such a serious topic is not easy, but writing an ACP makes a clear record of your wishes so that these can be respected (where possible).

How do I start planning?

To start with we would encourage you to have a conversation with your family about your wishes. You may be able to do this at your home or you might prefer a specially arranged meeting at the Renal Unit with a senior nurse.

You could also talk to your renal consultant or named nurse, or anyone you feel comfortable talking to and who would be willing to help you start to think about this.

When you are ready your wishes can be discussed in more detail with your preferred health care professional, these will be documented in your medical notes. This is so that anyone involved in your care is aware of your discussions. We would also write to your GP so that they too can support you in your planning.

What should I talk about?

It's normal to feel hesitant or worried about this type of conversation. You may worry about saying the wrong thing or upsetting people that you care about. However in our experience honesty and openness can often bring relief. Especially if you have already been considering what lies ahead for you in your future as a person with kidney disease.

You may want to make sure that your health care teams are aware of who you consider your next of kin and who you would like us to tell (or not tell) about your care or treatment. To make this legal you may want to appoint someone as a lasting power of attorney for health.

You may wish to discuss where you want to be with at the end of your life and who would look after you. Very ill people are at risk of dying, and may need cardio pulmonary resuscitation (CPR) if their heart stops beating. Sometimes resuscitation may cause more harm and will not help a person to live. We would encourage you to talk about with your family about CPR.

If you are on dialysis there may be some situations you may decide you don't want to continue dialysis. If you are not on dialysis you may decide this is not what you want to do should you develop severe kidney failure.

It is important to remember that advance care planning is not always a 'one off' conversation. The plan is not set in stone and you should feel comfortable to update it as your situation or priorities change.

If you have any questions or concerns that you feel we have not answered please speak to one of the team. If they don't know the answer they will contact a senior nurse who will be able to help you.

Is an Advance Care Plan a legal document?

Advance care planning is not legally binding but an informal statement of wishes and would be taken into account when decisions are made on your behalf.

Health care professionals have a duty to establish whether a person has capacity to make a decision to refuse or consent to treatment. This is a legal requirement under the mental capacity act.

Advance decision

An advance decision (sometimes known as advance decision to refuse treatment or living will) lets your healthcare team know about your wishes if you are no longer able to tell them. It is a document that allows you to refuse a specific treatment sometime in the future. The treatments you are refusing must all be named in the advance decision. An example might be: 'If I have a stroke which causes permanent loss of capacity I would want to stop dialysis'.

An advance decision needs to be written down, signed by you and a witness. You may find it helpful to talk to a doctor or nurse about the kind of treatments that may be offered to you in the future and what it means if you decide not to have them.

An advance decision to refuse treatment is legally binding if it complies with Mental Capacity Act, is valid and applies to the situation.

You can find more information on advance decisions from the NHS website: **www.nhs.uk/conditions/end-of-life-care/advance-decision-to-refuse-treatment**. The Compassion in dying website has an online form or paper form that you may find helpful.

Useful websites

Compassion in dying

This website has lots of information about planning for the future.

Website: www.compassionindying.org.uk/choose-a-way-to-make-an-advance-decision-living-will

Resuscitation council

This leaflet explains more about cardiopulmonary resuscitation.

Website:
www.resus.org.uk/public-resource/cpr-decisions-and-dnacpr

Government website

This site has information about make a lasting power of attorney.

Website: www.gov.uk/power-of-attorney

Mariecurie

Here you will find more information about planning for the future.

Website: www.mariecurie.org.uk/help/support/terminal-illness/planning-ahead/advance-care-planning

Government website

Information about the Mental Capacity Act.

Website: www.gov.uk/government/collections/mental-capacity-act-making-decisions

Oxford Kidney Unit

Lots of information about the Oxford Kidney Unit for patients and carers.

Website: www.ouh.nhs.uk/oku

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

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