Booklet for patients

# Advanced kidney disease

## Planning for end of life care

Patient Decision Aids are designed to help patients make difficult decisions about their treatments and medical tests. They are used when there is no clinical evidence to suggest that one treatment is better than another and patients need help in deciding which option will be best for them.

This Patient Decision Aid aims to help you consider planning for end of life care by thinking about whether you would like to take part in advance care planning.

Research shows that Patient Decision Aids are really effective in helping patients make informed choices about their healthcare and increase patients' awareness of the expected risks, benefits and likely outcomes.

This decision aid allows you to create a personal record which you can share with your health professional and use when discussing your options with them.

## Introduction

Many people with advanced kidney disease have long-term treatment plans which improve the quality of their life and help them to live well with their disease.

You may have been involved in making decisions and planning your care with the help of your doctors and other health or social care professionals throughout all the stages of your kidney disease so far.

This is fine while you are able to make your wishes known, but as your condition progresses, there may come a time when you are no longer able to make decisions for yourself about your care. It might be that you simply feel too unwell to express your wishes and preferences or make decisions, even though there may be things that are still important to you.

A way of exploring your wishes and preferences for your future care **and** enabling others to know about them is through the process of **advance care planning**. This is in case a time comes when you cannot express these wishes or decide for yourself.

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## Who the decision aid is for

This patient decision aid is for adults with advanced kidney disease whose condition falls into one of two categories:

The patient is not responding well to dialysis or transplantation and has decided to stop treatment, knowing that the end of life stage of kidney disease will eventually follow.

Or

The patient has opted for conservative kidney management rather than dialysis or transplantation, and has recognised that they are now approaching the end of life stage of their kidney disease.

## The purpose of the decision aid

It is hoped that the patient decision aid will help you decide if advance care planning is right for you.

Advance care planning can help you to:

- Make the most of your remaining life.
- Settle any issues regarding care, treatment options, and legal and financial issues.
- Plan for what you feel would be ‘a good death’.

You will find information explaining what advance care planning is and what you can include in it, for example:

- Your needs relating to your feelings, values, beliefs, wishes and your particular circumstances.
- Deciding who will act on your behalf to ensure that your wishes are respected.
- The issues around whether to have life-sustaining treatment or not.
- Where you would like to be cared for in your last days and where you would like to die.

You can go through the decision aid by yourself, or perhaps with the help of a family member, friend or a professional carer; but remember, this is all about **your** wishes for **your** future care.

**Please be aware that this decision aid is not about the decision to stop dialysis or anti-rejection treatment.**

## Kidney disease

- **Chronic kidney disease (CKD)** is any type of kidney disease that is long-lasting and does not get completely better over time but instead will generally deteriorate (National Kidney Federation, 2006).
- **Advanced kidney disease (AKD)** is a term used mainly to describe late stage 4 and 5 chronic kidney disease, where kidney function is severely decreased or there is established kidney failure (NHS Kidney Care and NEoLCP, 2009).

## About the decision aid

This decision aid is a tool to help you decide if you would like to take part in advance care planning either:

- Now.
- Not now but possibly later.
- Or you may decide that you don't want to take part in advance care planning.

You might decide that you are not ready to think about this yet or simply that you just do not wish to take part in advance care planning at all. That's fine; the advance care planning process is **entirely voluntary**. You don't have to take part, and if you do begin the process, you can change your mind at any time.

### Information available

**A DVD and this booklet**

- To give you information and get you to think about what your choices are.

**A questionnaire**

- To help us find out what your preferences are, fill in the questionnaire at the back of this booklet.

**A website -**

- You can access this information online at www.nhsdirect.nhs.uk/en/DecisionAids/PDAs/PDA_Advanced_Kidney_Disease.

## General care planning

### What is a care plan?

- A care plan takes account of the way that you live and your needs as they are now.
- A care plan recognises that there are other issues in addition to medical needs that can impact on your total health and well-being (Department of Health, 2009).
- Everyone with a long-term condition is entitled to a personalised care plan.
- Your personal care plan is agreed between you and a named healthcare professional to create a package of care that is centred on you and your needs; taking into account your physical and mental health, personal, social, economic and educational circumstances and ethnic and cultural background (Department of Health, 2008).
- If you are unable to make decisions for yourself, or make your wishes and preferences known, a care plan can be agreed and written by healthcare professionals on your behalf.
- To learn more about care planning for long-term conditions, visit ‘What is a care plan?’ on the NHS Choices website. http://www.nhs.uk/planners/yourhealth/pages/careplan.aspx

### Care planning for people with advanced kidney disease

As a person with advanced kidney disease, you have probably been involved in care planning before; perhaps with a written care plan that you helped to create to take account of your medical needs, personal interests and lifestyle choices, such as the My Kidney Care Plan (NHS Kidney Care, 2010).

A pilot study of patient-held kidney care plans at one NHS renal care unit found that 81% of patients who responded agreed the care plan had improved their care (Gerrard, 2011).

## What is advance care planning?

Whilst general care planning takes account of your needs and the way you live **now**, advance care planning is for when your illness is recognised as being ‘life limiting’. It helps to explore the choices you would like to make for your **future care** if a time comes when you lose capacity (the ability to make decisions for yourself).

## Capacity

Capacity is the ability to make a decision about a particular issue at the time the decision needs to be made, or to give consent to a particular act (National End of Life Care Programme, 2011).

The **key point of advance care planning** is that you are planning your end of life care and making decisions, while you are able to, about your care and treatment choices for a time in the future when you may not be able to make these decisions (National End of Life Care Programme, 2010).

**Advance care planning can only take place whilst you have the mental ability (capacity) to make decisions for yourself.**

**Your medical team, with the help of the other professionals involved with your care, would decide if and when this point is reached.**

## Key points about advance care planning

- It’s up to you how much involvement you have in your advance care planning.
- It’s a voluntary process.
- You may wish to discuss your wishes with your carers, partner or relatives.
- You can include anything that is important to you, no matter how trivial it seems.
- If you wish to refuse a specific treatment, you can consider making an advance decision to refuse treatment (ADRT).
- It is recommended that you seek the advice of an experienced healthcare professional if making an advance decision to refuse treatment.
- If you make an advance decision to refuse treatment that is life-sustaining it must be in writing, signed and witnessed.
- If you have named someone to speak for you or be consulted on your behalf, it will help to write down their name.

**... continued.**

- If you have appointed somebody as a Lasting Power of Attorney (LPA), again, write down their name.
- If your wishes are in writing, or if you have a Lasting Power of Attorney, keep a copy of the record safe.
- Provide copies for those who need to know your wishes, such as nurses, doctors, carers or family members. (National End of Life Care Programme, National Council for Palliative Care and University of Nottingham, 2009).

**In advance care planning you can make changes at any time.**

## Best interests

To determine a person’s best interests, their past and present wishes and feelings, beliefs and values should be taken into account.

These may be in an advance statement made by the person when they had capacity for those decisions or could be found in information recorded as part of the general care planning process.

Relatives and partners can give information about best interests but have no legal authority or right to make decisions for a person who lacks capacity, unless they have been granted such powers (by appointment as a Lasting Power of Attorney) by the person who now lacks capacity, or by the courts.

An assessment of a person’s best interests should also involve careful study (as far as is practical and possible) of any care records (such as clinical notes) to see if any advance statements of wishes, or valid and applicable advance decision to refuse treatment (ADRTs) exist; or if any other appropriate and applicable information exists about what the person’s views are.

These steps may not always be possible, for example if an individual is admitted to hospital as an emergency, is unconscious and requires rapid treatment.

(National End of Life Care Programme, 2011).

## Advance care planning for people with advanced kidney disease

Advance care planning can be started at any time, but once your kidney disease is acknowledged as life-limiting, it may be the right time to explore your options and the choices you would like to make for your future care and treatment. This can enable you to live your remaining life in the way that you have chosen; eventually leading up to what would be your idea of a good death.

Identifying when someone with advanced kidney disease is approaching the end of life care phase of their illness is important because it enables a change of emphasis from ‘cure and active prolongation of life’ to ‘symptom relief and maintenance of comfort’. This includes attention to psychological, social and spiritual concerns (NHS Kidney Care and NEoLCP, 2009).

You may have an assessment to decide whether supportive and palliative care is needed at **any point** in the management of your advanced kidney disease but specifically:

- If conservative kidney management is chosen.
- If your condition is ‘deteriorating despite dialysis’.
- Around the decision to withdraw from dialysis.
- At times of crisis, such as having a stroke or a new diagnosis of a terminal condition.
- If you have developed kidney failure as a result of other conditions or its treatment, such as cancer.
- Following kidney transplant failure when, after appropriate discussion by you with your family and the kidney team, a decision is made not to commence or recommence dialysis (NHS Kidney Care and NEoLCP, 2009).

It might be around events such as these, perhaps after talking to your family or professionals involved in your care, that you wish to start thinking about whether you would benefit from starting the advance care planning process.

## What can I include in advance care planning?

The wishes you express during advance care planning are personal to you and can be about anything to do with your future care (National End of Life Care Programme, National Council for Palliative Care and University of Nottingham, 2009).

Advance care planning might include your preferences, wishes, beliefs, values and feelings about:

- Personal goals or aspirations for care.
- Your illness and prognosis.
- The types of care or treatment that are available and their benefits, harms and risks.
- The types of decisions that may need to be made about your care and treatment in the future (NHS National End of Life Care Programme, 2011).

You may have wishes for your future care which you see as a priority. These can be included as part of your advance care planning process and can be anything, such as:

- Making others aware of any religious, faith or spiritual beliefs you may have.
- Naming a person who can be consulted by your healthcare professionals for advice about your future care.
- Stating your wishes about where you would prefer to die, for example in a care home, at home or in a hospice or hospital.
- Practical things relating to financial matters or perhaps arrangements for the care of your pets if you have them.

Your medical team and local care providers will probably have their own outline for advance care planning which they will use to lead discussions with you, but you should also have a **holistic common assessment** to identify your supportive and palliative care needs (National End of Life Care Programme, 2010a).

‘Holistic common assessment’ simply means that *all* of your needs are assessed, not just your physical needs. This includes your psychological, social, sexual, spiritual and cultural needs as well. It will often be done by your specialist nurse or a key worker involved in your care.

## Advance care planning might not be for you

Some people may have negative feelings about the process of advance care planning, because it may challenge their coping method or bring to mind issues about their illness and their future which they are not ready to think about.

Others are comfortable with such discussions but, should they lose capacity (the ability to make decisions for themselves) in the future, prefer to leave such decisions to their carers. (National End of Life Care Programme, 2011).

Advance care planning is entirely voluntary, so if you feel that it is **not** for you don’t worry; if you lose the ability to make decisions for yourself you will still be looked after, and you will be given care and treatment which is thought to be in your best interests.

**Whatever your decisions, the *quality* of your care will not be affected; advance care planning simply gives you the chance to choose the care that you would wish for yourself** (National Institute for Health and Clinical Excellence, 2011; Gold Standards Framework, 2011).

## When to start the advance care planning process

**You can start advance care planning at any time you choose.**

- You can begin advance care planning at any point in your life and perhaps the best time is when you are relatively well (Chambers, 2010).
- The right time for some people may be around the time of a change in focus of care objectives; once they are feeling fairly settled with their condition and ready to start thinking about future care.
- For some people with long-term conditions, advance care planning is included as part of their standard care plan.

## Who is involved in my advance care planning?

- You can include **anyone you want** to help in your advance care planning.
- You will need to talk to the healthcare and other professionals involved in your care, about what care and treatment is suitable for you and available to you. One of the benefits of advance care planning is that it enables co-ordinated planning and multi-professional working between teams linking kidney care, primary care, community care and palliative care services (NHS Kidney Care and NEoLCP, 2009).
- You do not have to speak to each care professional but everyone identified as having a role in your future care should be identified, named and informed of your treatment and care decisions.
- You will also need to talk to anyone you nominate to act on your behalf under a Lasting Power of Attorney and anyone you would like to be consulted about your preferences for care under an advance statement. These people will find it easier to represent your wishes or make decisions for you if you have discussed your choices and preferences for care with them.

- Finally, you may choose to involve close family members, other relatives or friends so that they are aware of your decisions and can support you.
- However, with this in mind, you need to be aware that advance care planning should reflect **your** choices for your future care, rather than the wishes of those close to you (although, of course, the wishes and feelings of your loved ones may be very important to you).

## Benefits of talking

These conversations may be difficult at first but a study based on interviews with people with end-stage renal disease (Davison and Simpson, 2006) found that advance care planning helped people with advanced kidney disease feel empowered by talking about their end of life care with healthcare professionals:

“By understanding their disease and the healthcare system they were now a part of and being able to predict to some extent the outcomes of their illness, they perceived greater control over their lives and how they were going to live with their disease.” (Davison and Simpson, 2006; p2).

They also found that this had benefits for their personal well-being and peace of mind: “Participants expressed greater feelings of isolation and less hope when they were not able to honestly and openly discuss their hopes and fears for the future with loved ones.” (Davison and Simpson, 2006; p3).

Many people find it difficult to talk about dying with those who are close to them. You might be concerned that you might upset your relatives, or are worried how they will react. As with anything that is difficult, it is always best to talk openly and honestly. You may find it useful to involve the doctors, specialist nurses or other members of the renal team. If there is a particular member of the team you have found easier to talk to, this may be the person you prefer to contact (Kidney Research UK, 2011).

## Starting the advance care planning process

There is no set framework for advance care planning and no specific topics that you need to discuss. This can sometimes make it hard for you and your care team to start a discussion.

As with general care planning, it can be useful to start by thinking about your health and your possible future medical needs.

# Outcomes

## Outcomes of advance care planning

As advance care planning depends on your ability (capacity) to make decisions, it is governed by the Mental Capacity Act 2005. It has formal outcomes that are legally binding or outcomes that must be taken into account by anyone acting on your behalf (National End of Life Care Programme, 2010).

Under the terms of the Mental Capacity Act 2005, formalised outcomes of advance care planning might include one or more of the following:

- **Advance statements** (previously called advance decisions or living wills).
- **Advance decisions to refuse treatment (ADRT).**
- **Lasting Power of Attorney (LPA)** - (National End of Life Care Programme, 2011; p10).

You can find out more about the Mental Capacity Act 2005 from the Government's Justice website.

## Advance statement

- An advance statement is where you can record your wishes about **any** aspect of your future care and treatment or social care, based on your feelings, values, beliefs and your own particular circumstances.
- It is written by you. It can be written with support from professionals, relatives and carers **whilst you have capacity** (the ability to decide for yourself).
- An advance statement helps others involved in your care to be aware of your wishes and preferences for your future care if a time comes when you lose capacity.
- Your wishes that are recorded in an advance statement can be a guide for those involved with your care as to what your best interests would be if you lose capacity.
- You might record your wishes in a Preferred Priorities for Care (PPC) plan which would be used as an advance statement.
- Whilst not legally binding, an advance statement must be taken into account by those involved with your care.
- It does not need to be signed, but a signature can help to make it clear who the wishes in the statement relate to.
- You can choose who else sees your advance statement, though the health and social care professionals involved in your care can help you decide who to share it with (National End of Life Care Programme, 2010).

If you did **not** have an advance statement, and a time came when you lost capacity, you would be given care and treatment **thought** to be in your best interests, but it might not necessarily be what you would have wanted.

Advance statements of your wishes for future care can be written or verbal. However, having your wishes recorded in writing means that there is more certainty for you and those who are involved in your care.

## Advance decision to refuse treatment (ADRT)

- An ADRT can be made as an option within an advance care planning discussion.
- It can be written or verbal.
- You can refuse to have any treatments that you do not want to have as part of your future care if a time comes when you lose capacity and cannot decide for yourself.
- You have to be specific about which treatment you are refusing for the future.
- An ADRT must be made by you, with support from your medical team if needed, whilst you have capacity and can decide for yourself.
- You can only use it to specify what treatment you do **not** want.
- If an ADRT is used to refuse life-sustaining treatment, it must be in writing and signed and witnessed. It must contain a statement that it applies even if your life is at risk.

- An ADRT cannot be used to demand treatment that would not work, or to request to end your life.
- It is legally binding if it complies with the Mental Capacity Act 2005 and is correctly made.
- It is up to you who sees your ADRT but your healthcare team will help you decide who to share it with (National End of Life Care Programme, 2010).
- Advance decisions to refuse treatment will **only** be acted upon if you **lose** capacity.

If you think you might want to make an ADRT you should speak to a healthcare professional involved in your care. They will be able to share the decision with you and guide you. Also speak to those close to you; it will help if they are aware of your wishes.

## Decision not to have cardiopulmonary resuscitation

This is also known as DNACPR, which stands for ‘do not attempt cardiopulmonary resuscitation’.

- If you stop breathing or have a cardiac arrest your medical team are responsible for making the decision about whether an attempt to resuscitate you is appropriate at the time.
- A decision by you **not** to have cardiopulmonary resuscitation (CPR) only covers the decision that you **don’t** want to be resuscitated if you stop breathing or have a cardiac arrest.
- A DNACPR requires a separate form.
- The form is legally binding but **only** if it is part of an advance decision to refuse treatment (ADRT).
- If you feel strongly that your views on cardiopulmonary resuscitation must be respected, you must include a DNACPR statement within your advance decision to refuse treatment (ADRT).
- Not everyone will need to have a DNACPR as part of advance care planning.
- This can be quite a complex matter. If you need to know more, you should talk to the medical and nursing professionals responsible for your care; they will guide you on this.

## Lasting Power of Attorney (LPA)

- A Lasting Power of Attorney is where you put in writing the name of someone you trust to make decisions or manage your financial, legal or health affairs on your behalf in the future if **you** are no longer able to do so (Macmillan Cancer Support, 2008).
- The person you appoint to act on your behalf is called your ‘attorney’. A Lasting Power of Attorney is completed in advance but cannot be used until it is registered with the Office of the Public Guardian (Office of the Public Guardian, 2009).
- You will continue to make your own decisions until a worsening of your physical or mental health means that your appointed attorneys have to make decisions for you (Office of the Public Guardian, 2009).
- Most people have a Lasting Power of Attorney to enable their family to sort out their property and financial affairs should they become incapable of looking after themselves. You may already have this type of Lasting Power of Attorney.
- Age UK have a detailed factsheet explaining the different types of LPAs; it explains why you may want to make arrangements for other people to make decisions about your welfare and finances (Age UK, 2010).

There are **two** types of LPA, they are:

1. Lasting Power of Attorney for Health and Welfare
2. Lasting Power of Attorney for Property and Affairs

## Lasting Power of Attorney for Health and Welfare

- This is a person of your choice, legally appointed as an ‘attorney’, who then has the legal authority to ensure your wishes about your care and treatment are respected if you lose capacity.
- You can choose more than one person to act as LPA for health and welfare if you wish.
- An LPA for Health and Welfare can make decisions about your health on your behalf if a time comes when you lose capacity.
- If you want your LPA for Health and Welfare to make decisions on life sustaining treatment for you, this must be made clear and documented specifically in the LPA document.
- You will continue to make your own decisions until you lose capacity, only then would a LPA have to make decisions on health and welfare in your best interests on your behalf.

## Lasting Power of Attorney for Property and Affairs

- This is a person of your choice, legally appointed as an ‘attorney’, who can make decisions for you about your financial, property or other legal affairs, if a time comes in the future when you lose capacity and are unable to make decisions for yourself.
- You can choose more than one person to act as LPA for Property and Affairs if you wish.
- An LPA will only come into effect in the event that you lose the capacity to make the decisions which are recorded in the LPA.
- You can continue to make these decisions for yourself while you still have the capacity to do so.
- An LPA for Property and Affairs does not have any authority to make decisions about your care or treatment at any time.

## Considerations

Things to give some further thought to in advance care planning

### Naming a person

- You may wish to name one or more persons who you would like to be consulted about your care if you are not able to make decisions for yourself.
- This person(s) would be able to provide information that will help your healthcare or other professionals act in your best interests.
- A named person would usually be someone who knows you well.
- This is not the same as an LPA, it is **not** legally binding.
- Your named person(s) can only **advise** your healthcare professionals, who may consult them about your wishes and preferences for your future care if you lose capacity.

### Palliative care

Palliative care is the active holistic care of patients with an advanced progressive illness. Management of pain and other symptoms, and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families (National Council for Palliative Care, 2011).

Palliative care services for people with advanced kidney disease will depend on the renal care or treatment you are receiving and any other conditions you may also have. It will also depend on the services available to you in your area. There may be palliative care services linked to your hospital's renal department, perhaps as a specialist hospital in-patient unit or a specialist hospice.

It is often thought that hospices are only for people who have cancer, however this is not the case; hospices can provide care in the final stages of any illness, regardless of the diagnosis.

## Preferred place for care

One of the most important decisions in advance care planning is where you would like to be cared for and who should care for you.

For people with advanced kidney disease this can be a complex decision depending on the type of treatment you are receiving or wish to receive; any other conditions or illnesses you have; **and** the availability of the right type of care and support services in your area.

The Department of Health have statistics for the number of people who choose to be cared for and die at home as opposed to hospital or other places. In 2008 statistics showed that more people chose to be cared for and die at home (National Audit Office, 2008).

Some people choose to be cared for and die in hospital, care homes or hospices, as well as at home. Everyone is different and you should choose what feels right for you.

This is a very important decision for you, perhaps *the* most important, and you should not be influenced unduly by statistics or what other people have chosen.

**Choose what is right for you.**

Speak to your healthcare team and your family; they will support you in your choice.

**Remember, you can change your mind about the place for your care at any time.**

It is not always possible to have your place of choice, depending on what services are available in your area, so speak to your healthcare team. They will be able to check what is available for you, so that you can make realistic choices.

Despite agreeing and recording your choice of a place for care, sometimes it is not possible to have care in your chosen place when the time comes. This may be due to unforeseen issues, such as lack of available beds. Again, speak to your healthcare team about the likelihood of this happening in your area.

## Organ and tissue donation

People with advanced kidney disease can be suitable as organ and tissue donors.

If you are interested in being a donor, you should speak to your family and your healthcare professionals.

It will help your family or those close to you if your wishes about this are recorded.

## Donating your body or brain for medical training and research

Body donation is less well known than organ donation. Human bodies are used to teach medical students about the structure of the body and how it works; they may also be used to train surgeons and other healthcare professionals.

You can register as both an organ and a body donor.

After your death, if your organs are suitable for transplant then they will be used to help the living and it is unlikely that your body will be accepted for medical training and research.

However, if after your death, your organs are not found suitable for transplant, then body donation to a medical school could be taken forward by your relatives and legal representatives, provided you have made your wishes known in writing.

Brain donation helps scientists improve their understanding of how diseases start and progress, and what keeps us healthy. Using brain tissue from deceased people who did not have diseases to compare with tissue from a person with a disease has helped with the discovery and treatment of diseases such as schizophrenia, Alzheimer’s disease, Parkinson’s disease and variant Creutzfeldt-Jakob Disease (vCJD).

You can find out more information on donating your body or brain for research on the Human Tissue Authority website. http://www.hta.gov.uk/

## Putting your affairs in order

There are practical and legal issues that you may want to consider when approaching the end of your life. These include accessing financial support and making choices regarding your care, your funeral and what happens to your possessions and money after your death.

## Weighing it up

[National End of Life Care Programme. 2011:NHS KidneyCare and NEoLCP 2009]

| Advantages of advance care planning | Things to be aware of in advance care planning |
|---|---|
| You can have control over what care and treatment you receive if a time comes when you are unable to express your wishes. | You have to be **specific**. You could still receive emergency treatment that you have **not specifically refused** if you had a sudden health crisis and could not make decisions for yourself. |
| Some people may feel that their relationships with others are stronger as a result of advance care planning. | Choices recorded in an advance statement about future care and treatment **will** be taken into account if you lose capacity. So you need to make sure that your plan is updated as your circumstances or views change. |
| Important decisions around advance decision to refuse treatment (ADRT) and Lasting Power of Attorney (LPA) can be included as part of the advance care planning process. | It can have negative effects for some people; it can challenge their coping style or bring to mind issues about their illness and their future which they are not yet ready to think about. |

| Advantages of advance care planning | Things to be aware of in advance care plan |
|---|---|
| Advance care planning can help people to anticipate the sort of decisions which may need to be made in the future as their disease progresses. | Others, while comfortable with such discussions, prefer to leave the decisions to their carers. |
| An advance statement can reduce the possibility of unwanted hospital admissions and emergency treatment. | An advance statement itself is *not* legally binding; however, it can contain additional instructions which *are* legally binding. |
| Having an agreed plan in place will help to enable you to spend your remaining days, and to die, in the place of your choice with the people of your choice. | The *quality* of care you receive will not be affected or reduced if you do not have an advance statement; although the type of care and treatment that you are given might not be what you would have chosen. |
| Your loved ones and others involved in your care will not have to make difficult decisions on your behalf. | Even with an advance statement in place, it may not be possible for all your wishes and choices to be carried out. This may apply, for instance, in the case of 'place of death' which is not covered by a legally binding decision. |

| Advantages of advance care planning | Things to be aware of in advance care plan |
|---|---|
| Advance care planning enables co-ordinated planning and multi-professional working between teams linking kidney care, community care and palliative care services. | Some decisions which require legal work will incur a cost. |

Whatever your decisions, the quality of your care will not be affected: advance care planning simply gives you the chance to choose the care that you would wish for yourself (National Institute for Health and Clinical Excellence, 2011; Gold Standards Framework, 2011).

## Support services and further information

- Age UK
- British Kidney Patient Association
- Carers UK
- Cruse Bereavement Care
- Dying Matters
- Help the Hospices (hospice information services)
- Kidney Research UK
- Marie Curie Cancer Care
- National Council for Palliative Care
- UK National Kidney Federation

## Questions to consider

Have you had an assessment of your needs recently?

Do you have any wishes or preferences for your future care that you need others to know about?

Do you think the time is right for you to start the advance care planning process?

Would you like to make an advance statement to record your wishes and preferences for your future care?

Are there any specific treatments that you think you would **NOT** want?

Do you wish to talk to your doctors or specialist nurses about ‘Do Not Attempt Cardiopulmonary Resuscitation’ (DNACPR)?

Do you think you need to appoint a Lasting Power of Attorney (LPA) for Health and Welfare?

Do you think you need to appoint a Lasting Power of Attorney (LPA) for Property and Affairs?

Is there anyone you would like to name who would be consulted about your care and treatment?

## Questions to consider (continued...)

Do you have an idea about where you would like to be cared for in your last days?

Would you like to record your wishes about organ and tissue donation?

Would you like to record your wishes about body and/or brain donation?

Do you need to settle any financial matters?

Do you need to check that you are not missing out on any benefits that you might be entitled to?

Do you need to make a will or review an existing will?

Would you like to talk about your wishes or arrangements for your funeral?

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The renal patients and carers who kindly helped us at every stage

## References

You can find important documents that we refer to in this booklet in a medical library or online at:

http://www.nhsdirect.nhs.uk/en/DecisionAids/PDAs/PDA_Advanced_Kidney_Disease?page=Support_Services_action&goTo=4#content

## Explanation of terms and words used in this booklet

**Advance decision to refuse treatment (ADRT):** The legal right to refuse certain treatments or medical procedures in certain circumstances, if you become incapable or unable to make your wishes for your treatment to be known.

**Advance statement:** A document you write (and needs to be witnessed by another person) giving your views on how you would like or not to receive treatment if you became incapable of communicating your wishes. An advance statement is not legally binding, but should be considered by those providing your treatment.

**Capacity:** The mental ability to make a decision about a particular treatment issue at the time the decision needs to be made.
Cardiopulmonary resuscitation: Also known as CPR or mouth-to-mouth resuscitation. A set of emergency treatments (breathing and chest compressions) designed to restart the heart and restore breathing to someone whose heart and breathing has stopped.

**Conservative kidney management:** Conservative treatments are ones which are used when other treatments have been tried and failed or where they would not be expected to make much difference to a person’s quality of life and the treatment would not make any improvement to their condition.

**Lasting power of attorney:** A legal document which allows you to appoint someone to make decisions on your behalf if you are unable or incapable of doing so yourself. Decisions can be made about your health and treatment, legal matters, money or property.

**Mental Capacity Act 2005:** The legal Act for enabling people to make their own decisions on matters personal to them such as their health, finances or day-to-day living - if they have the mental capacity to do so. The Act provides details of how to determine whether someone is mentally capable.

**Palliative care:** The type of care which deals with and manages the symptoms of long term or life- limiting conditions. Palliative care is offered towards the end of life to make the person more comfortable and so they have the support they need.

This booklet is designed for patients with advanced kidney disease.

In order to access the NHS Direct Advanced Kidney Disease Planning for End of Life Care online Patient Decision Aid please visit the following web site address:

http://www.nhsdirect.nhs.uk/decisionaids/PDAs/PDA_Advanced_Kidney_Disease