

Understanding NICE guidance

Information for people who use NHS services

Identifying and treating long-term kidney problems (chronic kidney disease)

NICE 'clinical guidelines' advise the NHS on caring for people with specific conditions or diseases and the treatments they should receive.

This booklet is about the care and treatment of people with long-term kidney problems (also called chronic kidney disease) in the NHS in England and Wales. It explains guidance (advice) from NICE (the National Institute for Health and Clinical Excellence). It is written for people with chronic kidney disease but it may also be useful for their families or carers or for anyone with an interest in the condition.

The booklet aims to help you understand the care and treatment options that should be available in the NHS. It does not describe chronic kidney disease or the tests or treatments for it in detail. A member of your healthcare team should discuss these with you. There are examples of questions you could ask throughout this booklet to help you with this. Some sources of further information and support are on page 10. Medical terms printed in **bold type** are explained on page 11.

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The advice in the NICE guideline covers:

- the tests doctors should use to diagnose long-term kidney problems (chronic kidney disease)
- the best treatment and care for adults diagnosed with chronic kidney disease, and when they should be referred to specialist renal services
- the general management of chronic kidney disease from a variety of causes including diabetes, high blood pressure and cardiovascular disease.

It does not specifically look at the care of:

- children (aged under 16 years)
- people receiving kidney dialysis or who have had a kidney transplant
- pregnant women with chronic kidney disease
- people with short-lasting damage to their kidneys.

Your care

Your treatment and care should take into account your personal needs and preferences, and you have the right to be fully informed and to make decisions in partnership with your healthcare team. To help with this, your healthcare team should give you information you can understand and that is relevant to your circumstances. All healthcare professionals should treat you with respect, sensitivity and understanding and explain chronic kidney disease and its treatment simply and clearly.

The information you get from your healthcare team should include details of the possible benefits and risks of particular treatments. You can ask any questions you want to and can always change your mind as your treatment progresses or your condition or circumstances change. Your own preference for a particular treatment is important and your healthcare team should support your choice of treatment wherever possible.

Your treatment and care, and the information you are given about it, should take account of any religious, ethnic or cultural needs you may have. It should also take into account any additional factors, such as physical or learning disabilities, sight or hearing problems, or difficulties with reading or speaking English. Your healthcare team should be able to arrange an interpreter or an advocate (someone who supports you in putting across your views) if needed.

If you agree, your family and carers should have the chance to be involved in decisions about your care. Family members and carers also have the right to the information and support they need in their roles as carers.

If people are unable to understand a particular issue or are not able to make decisions for themselves, healthcare professionals should follow the advice that the Department of Health has produced about this. You can find this by going to the Department of Health website (www.dh.gov.uk/consent). Your healthcare professional should also follow the code of practice for the Mental Capacity Act. For more information about this, visit www.publicguardian.gov.uk

If you think that your care does not match what is described in this booklet, please talk to a member of your healthcare team.

Chronic kidney disease

Long-term kidney problems (chronic kidney disease) occur when the kidneys don't work as well as normal. Chronic kidney disease is quite common, and people often have the condition without knowing it. In many people when the kidneys are working only slightly less well than usual there may not be any symptoms and they may not need any treatment.

Chronic kidney disease can be caused by several conditions, including diabetes and high blood pressure. It is classified into stages depending on how advanced it is (see the table below). Stages 4 and 5 are sometimes called **advanced chronic kidney disease**.

Tests for chronic kidney disease

There are simple tests that can tell whether you have a kidney condition or not. For example, a blood test can be used to estimate your **GFR** (or **glomerular filtration rate**). This is a measure of how well your kidneys are working. A urine sample can show if there is protein in your urine (this is called **proteinuria**), which can also be a sign that your kidneys are not working properly. You should be offered these tests if you are at risk. For example, you may be at risk if you have certain other conditions such as high blood pressure or diabetes, or if there is a history of kidney disease in the family (see the box at the top of page 5).

The following table shows how the GFR relates to the different stages of chronic kidney disease and what this means in terms of diagnosis. Stages 3–5 can be diagnosed by GFR alone, but stages 1 and 2 also need other evidence of kidney damage, such as proteinuria. Generally, the higher your GFR, the healthier your kidneys are.

Stages of chronic kidney disease*

Stage	GFR	Description
1	90 or over	Normal or increased GFR, with other evidence of kidney damage
2	60–89	Slight decrease in GFR, with other evidence of kidney damage
3A	45–59	Moderate decrease in GFR, with or without other evidence of kidney damage
3B	30–44	
4	15–29	Marked decrease in GFR, with or without other evidence of kidney damage
5	Under 15	Kidney failure

* Stage 3 chronic kidney disease has been divided into 3A and 3B to help clinicians manage the condition more effectively.

People who should be offered testing

If you have any of the following you should be offered tests for chronic kidney disease:

- diabetes
- high blood pressure
- cardiovascular disease
- structural renal tract disease, kidney stones or an enlarged prostate
- diseases that affect several parts of the body and may affect the kidneys, such as systemic lupus erythematosus
- a family history of stage 5 chronic kidney disease or an inherited kidney disease
- blood in your urine (this is called haematuria) or protein in your urine (**proteinuria**) where there is no known cause.

Ultrasound scan

If you have been diagnosed with chronic kidney disease and have any of the following you should be offered an **ultrasound scan**:

- kidney function that is getting a lot worse
- blood in your urine
- symptoms of **urinary tract obstruction**
- you are aged over 20 and have a family history of **polycystic kidney disease**
- stage 4 or 5 chronic kidney disease
- you need a **kidney biopsy**.

This scan will help doctors to see any problems with your kidneys or bladder.

If you have a family history of a kidney disease that may be inheritable your doctor should talk to you before the scan about what it will mean if you have an abnormal result.

Things that can make your kidney condition worse

When kidneys get diseased, they can sometimes continue to get worse over months or years. This is called progressive kidney disease. Your doctor will be able to tell whether you have progressive kidney disease by checking your kidney function regularly.

Your kidney disease is more likely to be progressive if you:

- have cardiovascular disease
- have protein in your urine
- have high blood pressure
- have diabetes
- smoke
- are of black or Asian ethnicity
- take non-steroidal anti-inflammatory drugs (**NSAIDs**) for a long time – for example, if you have arthritis or another long-term, painful condition
- have **urinary tract obstruction**.

If you have any of these risk factors your healthcare professional should work with you to make sure your health is as good as it can be, as this can help slow down the progression of your kidney disease. They should also check your kidney function regularly.

Questions you might like to ask about chronic kidney disease

- Can you give me more details about the tests I should have?
- How will I know if my kidney disease is getting worse?
- Will my kidney disease affect treatments for other conditions I have?
- What are the pros and cons of having this treatment?
- Are there any support organisations in my local area?
- What will happen if I decide not to have a scan?

Referral to a specialist

Many people with chronic kidney disease can be treated by their GP and may not need to see a specialist. Your GP may discuss your case with the specialist by phone, letter or email and you may not need to go to a hospital.

But there are some cases where your GP should offer to refer you to a specialist. This may be if you have any of the following:

- stage 4 or 5 chronic kidney disease
- a large amount of protein in your urine (unless you have diabetes and are already being treated for this)
- both protein and blood in your urine
- kidney function that is quickly getting worse
- blood pressure that remains high even though you are taking at least four different types of medicines to control it
- a suspected or confirmed rare or genetic cause of chronic kidney disease
- suspected narrowing of the arteries to your kidneys (**renal artery stenosis**)
- **urinary tract obstruction.**

After you have been referred and a plan has been made to manage your kidney disease, your GP may be able to do your regular check-ups, and you may not need to continue to see the specialist.

Some treatments may not be suitable for you, depending on your exact circumstances. If you have questions about the specific treatments and options covered in this booklet, please talk to a member of your healthcare team.

High blood pressure

People with chronic kidney disease often have high blood pressure, and this can damage the kidneys further. Therefore your doctor may offer you medicine to help control your blood pressure. Even if you don't have high blood pressure, you may be offered these medicines to help prevent your kidney disease from getting worse. Your doctor will look at the levels of protein in your urine before deciding whether to do this and will discuss it with you.

There is a wide range of medicines that can be used for controlling your blood pressure if you have chronic kidney disease. Two types of medicines you are likely to be offered, particularly if you have protein in your urine, are **ACE inhibitors** (this stands for **angiotensin-converting enzyme inhibitors**) or **angiotensin-II receptor blockers**. You may need to try different doses of these medicines to find the right dose for you. To make sure this is done safely you will have your GFR and blood potassium levels monitored (this is done by blood tests). This should happen before you start taking the medicines, 1 or 2 weeks after you start, and each time the dose is increased.

Cardiovascular disease

Cardiovascular disease means disease of the heart or blood vessels. Because chronic kidney disease puts you at a higher risk of heart attacks and strokes, your doctor will want to make sure that your risk is reduced. You may be offered medicines called statins, which lower the level of cholesterol in the blood and reduce the risk of cardiovascular disease. You may also be offered anti-clotting medicines such as low dose aspirin. These medicines help to thin the blood and prevent blood clots forming in your arteries. Your doctor will look at your personal risk of cardiovascular disease before deciding whether these treatments will be beneficial for you.

You should also be encouraged to stop smoking. This is at least as important as these medicines in reducing the risk of cardiovascular disease.

Bone disease

Kidneys play an important role in keeping the bones healthy. If you have stage 4 or 5 chronic kidney disease you might develop problems with your bones over the long term. This is called renal bone disease. Therefore the levels of calcium, phosphate and a hormone called **parathyroid hormone** in your blood will be monitored if you have stage 4 or 5 chronic kidney disease.

Anaemia

Kidneys have an important role in keeping your blood healthy. People with chronic kidney disease may develop **anaemia**. If you have stage 3B, 4 or 5 chronic kidney disease you should be offered a blood test to see if you have anaemia. NICE has produced guidance on treating anaemia in people with chronic kidney disease¹. If you are anaemic and have chronic kidney disease, it does not necessarily mean that your anaemia is caused by the kidney disease – there are many other possible causes of anaemia.

Diabetes

Having diabetes can increase the risk of developing kidney disease. This is because diabetes can damage the kidneys. If you have diabetes your doctor will make sure you are tested regularly to check whether you have kidney disease. This will usually be done at least once a year and will involve having your blood and urine tested. If you have diabetes your chronic kidney disease may need treatment that is different from people who do not have diabetes.

Lifestyle advice

People with chronic kidney disease should be encouraged to take exercise and achieve a healthy weight. If your condition is getting worse you may be offered advice on diet. If it is thought that changing your diet may slow down the progression of the disease, a healthcare professional should discuss with you the pros and cons of restricting the amount of protein in your diet.

You should be offered education and information that is relevant to the cause of your kidney disease, how advanced it is, any complications you may have, your chances of it getting worse and what you can do to help prevent this happening. This will help you to understand your treatment and make informed choices about it.

If a treatment described in this booklet appears suitable for you, but it is not available, you should talk to your local Patient Advice and Liaison Service (PALS) in the first instance. If they are not able to help you, they should refer you to your local Independent Complaints Advocacy Service.

¹ See Understanding NICE guidance for 'Anaemia management in people with chronic kidney disease' (NICE clinical guideline 39). Available from www.nice.org.uk/CG039/PublicInfo

More information

The organisations below can provide more information and support for people with chronic kidney disease. Please note that NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

- National Kidney Federation, www.kidney.org.uk, 01909 544999
- Kidney Research UK, www.kidneyresearchuk.org, 0845 070 7601
- The Kidney Alliance, www.kidneyalliance.org, 01483 724472
- Diabetes UK, www.diabetes.org.uk, Careline: 0845 120 2960
- Polycystic Kidney Disease Charity, www.pkdcharity.org.uk, 01388 665004

NHS Direct online (www.nhsdirect.nhs.uk) may also be a good starting point for finding out more. Your local Patient Advice and Liaison Service (PALS) may also be able to give you further information and support.

Explanation of medical words and terms

Advanced chronic kidney disease Sometimes referred to as stage 4 or 5 chronic kidney disease. It is characterised by a **glomerular filtration rate** (see below) of less than 30.

Anaemia A condition where there are fewer red blood cells in the blood than normal.

Angiotensin-converting enzyme inhibitors (ACE inhibitors) and angiotensin-II receptor blockers These medicines help to reduce blood pressure and also to reduce the amount of proteinuria, if it is present.

Glomerular filtration rate (GFR) How much fluid (in millilitres) the kidneys can filter in a minute. Healthy kidneys normally have a GFR of around 100. A blood test used to estimate your GFR is often called an estimated GFR or eGFR.

Kidney biopsy A procedure that involves sampling a small piece of the kidney to look at under the microscope and carry out tests. It is used to make a diagnosis of the underlying cause of kidney disease or to show how advanced the kidney condition is.

NSAIDs Non-steroidal anti-inflammatory drugs (NSAIDs) can be used to treat several conditions such as pain, fever and conditions that cause inflammation, such as rheumatoid arthritis. Examples include aspirin and ibuprofen.

Parathyroid hormone A hormone that stimulates special cells in the bone to increase the amount of calcium and reduce the amount of phosphate in the blood.

Polycystic kidney disease A condition where many cysts develop in both kidneys. It can cause kidney failure and is usually inherited (but not always).

Proteinuria The presence of protein in the urine. It can be detected by a simple urine test.

Renal artery stenosis A condition where one or both of the arteries supplying blood to the kidneys becomes narrower. This can cause high blood pressure and sometimes leads to progressive kidney disease.

Ultrasound scan A procedure used to make an image of an organ in the body by using sound waves at very high frequency.

Urinary tract obstruction A condition where there is a block in the normal flow of urine in the urinary tract (the parts of the body that make and discharge urine). It can be caused by a kidney stone or an enlarged prostate gland, for example.

About NICE

NICE produces guidance (advice) for the NHS about preventing, diagnosing and treating different medical conditions. The guidance is written by independent experts including healthcare professionals and people representing patients and carers. They consider the best available evidence on the condition and treatments, the views of patients and carers and the experiences of doctors, nurses and other healthcare professionals working in the field. Staff working in the NHS are expected to follow this guidance.

To find out more about NICE, its work and how it reaches decisions, see www.nice.org.uk/aboutguidance

This booklet and other versions of this guideline aimed at healthcare professionals are available at www.nice.org.uk/CG073

You can order printed copies of this booklet from NICE publications (phone 0845 003 7783 or email publications@nice.org.uk and quote reference N1687).

We encourage NHS and voluntary sector organisations to use text from this booklet in their own information about chronic kidney disease.