

Understanding NICE guidance

Information for people who use NHS services

Treating anaemia in people with 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 **anaemia of 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 anaemia of 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 anaemia of 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 11.



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The advice in the NICE clinical guideline covers:

- detecting and diagnosing anaemia of chronic kidney disease
- managing anaemia of chronic kidney disease, and other health problems or treatments that may affect it.

It does not specifically look at:

- anaemia in people with chronic kidney disease, where the anaemia may be caused by other problems.

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 anaemia of chronic kidney disease and the treatments for it 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 asking for what you want) if needed.

If you agree, your carers and relatives (including parents where appropriate) should have the chance to be involved in decisions about your care. Carers and relatives 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 and are not able to make decisions for themselves, healthcare professionals should follow the advice that the Department of Health has produced about this (available from www.dh.gov.uk). Note: young people aged 16 and above are presumed to be able to consent to treatment themselves, unless there are exceptional circumstances.

Anaemia in people with chronic kidney disease

People with chronic kidney disease may develop anaemia. This can be for a number of reasons, one of which is a low level of a chemical messenger called erythropoietin (EPO for short). EPO is made in the kidneys and tells the body to make red blood cells (which happens in the bone marrow, at the centre of large bones). If a person has chronic kidney disease, the EPO level can drop so the body doesn't make enough red blood cells. It's the job of red blood cells to carry oxygen around the body. If there's not enough oxygen getting to the different parts of your body because you're low in red blood cells (anaemic), you may feel tired or short of breath.

If you have chronic kidney disease and you're diagnosed with anaemia (see page 5), one or more healthcare professionals should have main responsibility for your care and prescribe your medicine and monitor how well it works. You should have a point of contact if you have any questions, and you and your family or carers should also be offered opportunities to learn more about the condition. The information you're given should be suitable for you and relevant to your individual and current circumstances. The key areas that should be covered include:

- the causes, symptoms and treatment of the anaemia
- the support available for you
- living with anaemia (for example, eating healthily, the benefits of taking exercise, meeting others in the same position).

Diagnosing anaemia

If you seem to be anaemic but it's not clear whether you have chronic kidney disease, a blood test should be carried out to see how well your kidneys are working (called the estimated glomerular filtration rate). If the result shows you might have chronic kidney disease, you may need other blood tests.

Iron is needed to make red blood cells so these tests look at whether you have low levels of iron (iron deficiency). They also look at the levels of haemoglobin in your blood (haemoglobin is the substance that carries oxygen in the red blood cells). Some people may be offered a test to measure EPO levels, but this isn't helpful for most people.

Your healthcare professional should explain what tests you should have, what your results are and what they mean for you. The table on page 6 describes the various blood tests you may have.

Questions you might like to ask about being diagnosed with anaemia

- How might anaemia make me feel?
- Can you give me more details about the tests I should have?
- What do these tests involve?
- Can you direct me to some support organisations in my local area?
- Can you provide information for my family/carer?

Blood tests for diagnosing anaemia in chronic kidney disease

Test	What does it measure?	What is it used for?
Estimated glomerular filtration rate (GFR)	To measure how well the kidneys are working	This can show whether the anaemia is caused by chronic kidney disease or if another cause is more likely
Haemoglobin (Hb) level	To measure the level of the oxygen-carrying substance in red blood cells	If the result is too low, the anaemia may need treatment
Serum ferritin	To work out how much iron is stored in the body	This can show if a person is iron deficient Depending on serum ferritin levels, another test may also be needed: either hypochromic red cells, or transferrin saturation (see below)
Hypochromic red cells	To measure the number of red blood cells that are low in haemoglobin	This can show if the person is iron deficient and would benefit from intravenous iron treatment (injections of iron into a vein)
Transferrin saturation	To work out the amount of iron in the bloodstream	This can show if the person is iron deficient and would benefit from intravenous iron treatment (injections of iron into a vein)

Treating anaemia

One of the treatments for anaemia is an injection of a medication that works like natural EPO to encourage the body to make more red blood cells. This is called an ESA (ESA stands for erythropoiesis-stimulating agent), although you will usually hear the injections referred to as EPO injections. ESAs do not work well if the person also has an iron deficiency, so you should also have iron treatment if you have low iron levels and are having an ESA (see page 8).

There are different ESAs available, and your healthcare professional should try to find the one that will suit you best. He or she should explain the differences between the ESAs that are available to you, and discuss whether you want to inject yourself or have a healthcare professional to help. You should also discuss how often this should be done, how you're likely to cope with the injections, and the different ways of supplying ESAs and storing them. This should be agreed in a plan, and the plan should be reviewed if your needs change. If you are taking an ESA it is important that your blood pressure is monitored.

Information and support you should have if you're considering ESA treatment

- Information on why ESA treatment is needed, how it works, and the possible benefits and side effects (your GP should also have this information).
- Information about the importance of taking the ESA injection as directed and what could happen if you don't.
- Arrangements should be made so that you can get your ESA as easily as possible if you are going to inject it yourself.

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.

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.

Treatment with ESAs

You should be offered an ESA if it is likely to benefit you (some people are so ill or have other medical problems that mean they wouldn't feel any benefit from ESA treatment). The decision about whether to offer you an ESA should be based on your suitability for treatment, regardless of your age.

If it's uncertain whether you would benefit from taking an ESA, you should be able to try taking one for a trial period, if you want to, to find out how it affects you. Your healthcare professional should discuss the pros and cons of ESA treatment with you, and your carers if appropriate (see the box on page 7 for details of the information you should have if you're considering ESA treatment).

Iron deficiency

If you have an iron deficiency, this should be treated. If you are going to try an ESA, the iron deficiency should be treated, either by taking iron tablets or by having iron injections. Your healthcare professional should discuss with you how this will be done. The dose should be reviewed to make sure you are not storing too much iron. If you are going to try an ESA, the iron deficiency should be treated before or at the same time you start ESA treatment.

Once your iron levels are okay, your healthcare professional should discuss whether or not you need to keep taking iron supplements. If you're taking an ESA, you will need to continue taking iron, either in tablet form or as an injection. Your healthcare professional should explain the iron levels that you're aiming for.

Continuing with ESAs

Once you've tried an ESA for an agreed time, you, your carer and your healthcare professional should discuss how the trial went and agree whether to continue or stop the ESA treatment.

Your healthcare professional should review your blood tests and discuss how the ESA treatment is going and whether or not it might be beneficial to change to a different ESA. It may be necessary to adjust your dose and how often you have an injection to keep your haemoglobin levels stable. If your haemoglobin level changes unexpectedly, you should have tests to find the reason so that it can be treated.

Questions you might want to ask about ESA treatment

- Can you tell me why you have decided to offer me this particular type of treatment?
- What are the pros and cons of following the treatment you've recommended?
- Please tell me about what the treatment involves.
- How will the treatment help me? What effect will it have on my symptoms and everyday life? What sort of improvements might I expect?
- How long will it take to have an effect?
- Will I always need this treatment?
- Are there risks associated with this treatment?
- What are my options for treatments other than the recommended treatment?
- Is there some written information about the treatment I could have?

Hyperparathyroidism

If you have increased levels of a hormone called parathyroid hormone (known as hyperparathyroidism, which is usually a result of the kidneys not working well), your healthcare professional should consider whether treating it will help your anaemia, and discuss this with you.

Monitoring anaemia treatment

The box below shows the blood tests you should have to check how your anaemia treatment is going. Your healthcare professional should explain what results you're aiming for.

Tests that you should have regularly

Blood test	When you should have it
To check iron levels: <ul style="list-style-type: none">• serum ferritin, plus• hypochromic red cells or transferrin saturation	<ul style="list-style-type: none">• Every 4 weeks to 3 months (but not within a week of having an iron injection into a vein)
To check red blood cells: <ul style="list-style-type: none">• full blood count to check haemoglobin levels	<ul style="list-style-type: none">• Every 2–4 weeks when you're starting ESA treatment• Every 1–3 months once your ESA treatment is settled• More often if your ESA dose has been changed recently <p>You and your healthcare professional should discuss where this is done so that it is as convenient for you as possible.</p>

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

If ESAs aren't working

Some people continue to have low numbers of red blood cells despite having ESA treatment. Their haemoglobin level remains low or they continue to need high doses of ESA to stay at the target haemoglobin level. If this happens to you, your healthcare professional will check for causes (for example, it might be happening because you're losing blood for some reason or there's another medical problem). If there doesn't appear to be another cause, the problem could be related to the effects of your kidney disease or to the ESA treatment itself. Your healthcare professional will discuss the further tests and treatment that might be needed if this seems to be the case.

Treatments you don't need for anaemia

The following treatments have not been shown to be of extra benefit for anaemia of chronic kidney disease, although you may still be taking them for other reasons:

- medicines called androgens
- nutritional supplements, such as vitamin C, folic acid or carnitine.

If having a kidney transplant is an option for you, blood transfusions should be avoided where possible. However, sometimes transfusions may be necessary because of your medical condition.

More information about anaemia of chronic kidney disease

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

- National Kidney Federation, telephone helpline 0845 601 0209 (low cost call), www.kidney.org.uk

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.

About NICE

NICE produces advice (guidance) 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/CG039

You can order printed copies of this booklet from the NHS Response Line (phone 0870 1555 455 and quote reference N1116).