

Diagnosing and treating anaemia in people with chronic kidney disease

Information for the public

Published: 3 June 2015

nice.org.uk

About this information

NICE guidelines provide advice on the care and support that should be offered to people who use health and care services.

This information explains the advice about diagnosing and treating anaemia in people with chronic kidney disease (or CKD for short) that is set out in NICE guideline 8.

This is an update of advice on treating anaemia in people with chronic kidney disease that NICE produced in 2011.

Does this information apply to me?

Yes, if you are a child, young person or adult with chronic kidney disease.

It does not cover anaemia that is not caused by chronic kidney disease.

Anaemia in people with chronic kidney disease

Red blood cells carry oxygen using a protein called haemoglobin. A person develops anaemia when their levels of red blood cells are low and not enough oxygen gets to different parts of the body.

Symptoms of anaemia include feeling tired and shortness of breath. Anaemia is often caused by a shortage of iron (called iron deficiency) because iron is used to make red blood cells.

In chronic kidney disease, anaemia is mainly caused by low levels of a hormone called erythropoietin (EPO for short). EPO is made by the kidneys and tells the body to make red blood cells. In someone with chronic kidney disease, their levels of EPO can be low, meaning their body doesn't make enough red blood cells, causing anaemia.

If you have chronic kidney disease and you're diagnosed with anaemia (see [diagnosing anaemia in people with chronic kidney disease](#)), at least one healthcare professional should have main responsibility for your care. You should have someone you can 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, advice on eating healthily, the benefits of exercising, and meeting others with the same condition).

Your care team

A range of professionals who specialise in different areas of treatment or support may be involved in your care. These could include specialist doctors and nurses, pharmacists, dietitians, physiotherapists and GPs. All of these professionals will be trained and experienced in providing particular treatments or support.

Working with you

Your care team should talk with you about anaemia in chronic kidney disease. They should explain any tests, treatments or support you should be offered so that you can decide together what is best for you. Your family or carer can be involved in helping to make decisions, but only if you agree. If you are a child or young person, your parent or carer may be involved in helping to make decisions depending on your age. There are questions throughout that you can use to help you talk with your care team.

You may also like to read NICE's information for the public on [patient experience in adult NHS services](#). This sets out what adults should be able to expect when they use the NHS. We also have more information on the NICE website about [using health and social care services](#).

Some treatments or care described here may not be suitable for you. If you think that your treatment does not match this advice, talk to your care team.

Diagnosing anaemia in people with chronic kidney disease

If your symptoms suggest you might have anaemia, or if you have anaemia but it's not known if it's caused by chronic kidney disease, you should be offered tests to investigate this. Your anaemia specialist should explain any tests you may have and what the results mean. The table below describes the various blood tests you may have. How often you are tested, what test you might be offered and your response to treatment will depend on your symptoms and your stage of chronic kidney disease.

Blood tests for diagnosing anaemia in chronic kidney disease

Test	What does it measure?	What is it used for?
Estimated glomerular filtration rate (eGFR)	How the kidneys are working	To help find out whether or not the anaemia is caused by chronic kidney disease
Haemoglobin (Hb) level	How much haemoglobin is in red blood cells (haemoglobin carries oxygen)	To help find out whether the anaemia needs to be treated
Percentage of hypochromic red cells	The number of red blood cells that don't have enough haemoglobin	To show whether you have low levels of iron and would benefit from iron therapy
Reticulocyte haemoglobin content	The level of haemoglobin in immature red blood cells ^a	

If the tests 'percentage of hypochromic red cells' and 'reticulocyte haemoglobin content' are not available you should be offered the test below.

Serum ferritin and transferrin combination	How much iron is in the blood	To show whether you have low levels of iron and would benefit from iron therapy
^a Immature red blood cells are red blood cells that are developing in the bone marrow.		

Questions to ask about being diagnosed with anaemia

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

Treating anaemia in people with chronic kidney disease

If you are diagnosed with anaemia, you may be offered treatment with iron, or an erythropoiesis-stimulating agent (often called an ESA), or both, depending on the cause of the anaemia. Iron can be used to treat anaemia if you have low levels of iron (called iron deficiency). ESAs can also be used to treat anaemia because they work like natural erythropoietin (EPO for short) to encourage the body to make more red blood cells. Low EPO levels are the main cause of anaemia in people with chronic kidney disease.

Treatment with iron

If you need treatment with iron, your anaemia specialist should discuss with you how this will be done and offer you iron tablets or iron infusions (iron injections given using a drip or in a single injection). The amount of iron you are taking should be checked to make sure you are not storing too much iron. Too much iron can be bad for your liver. If you are going to try taking an ESA to treat

the anaemia (see [treatment with ESAs](#)), the iron deficiency should be treated before or at the same time you start ESA treatment.

If you are not taking ESAs

If you have low iron levels and you are not taking ESAs, you should be offered treatment with iron. Your anaemia specialist should discuss with you the risks and benefits of the different treatment options. If you are not having haemodialysis (or kidney dialysis – a procedure to remove fluid and waste products from the blood), you might be able to try taking iron tablets for a trial period to treat your low iron levels, rather than having iron infusions. If this works, you may not need to have iron infusions. But if taking iron tablets is causing you problems you should be offered iron infusions.

If you are having haemodialysis, you should be offered iron infusions. But if iron infusions wouldn't be suitable for you, or you choose not to have them, you should be offered iron tablets.

Your doctor should discuss the results of the iron treatment with you (and your family or carers, if appropriate) and offer you ESA therapy if they think it would benefit you (see 'treatment with ESAs'). But if the iron treatment has been successful you may not need to have ESA therapy.

If you are taking ESAs

Adults and young people

If you are aged 14 years or over, you are already taking ESAs (see 'treatment with ESAs') and your iron levels become too low, your anaemia specialist should discuss with you the risks and benefits of possible treatments for this. You should be offered iron infusions. But if you choose not to have iron infusions, or iron infusions wouldn't be suitable for you, you should be offered iron tablets instead.

Children

If you are aged 13 years or younger, you are taking ESAs (see 'treatment with ESAs') and having haemodialysis, your anaemia specialist should discuss treating your iron deficiency with you (and your family or carers, if appropriate) and the risks and benefits of the different treatment options. You should be offered iron infusions.

If you are taking ESAs but you are not having haemodialysis, you may be offered iron tablets rather than iron infusions. But if you have problems taking the iron in tablet form, or your haemoglobin levels are still too low after 3 months, you should be offered iron infusions.

If you are having haemodialysis at home

If you are having haemodialysis at home, and you are offered iron infusions, you may need to have the iron infusions in a centre that has the medical facilities you might need if you became very unwell.

Off-label use of iron infusions

At the time of publication iron infusions may be recommended for '[off-label](#)' use for children and young people in this guideline. Your doctor should tell you this and explain what it means for you.

Continuing with iron

Once your iron levels are okay, your anaemia specialist should discuss whether or not you need to keep taking the iron. But if you are taking an ESA, you will need to continue taking iron, either in tablet form or as an infusion. Your anaemia specialist should explain the iron levels that you are aiming for. (See [tests for checking if your anaemia treatment is working](#).)

Treatment with ESAs

One of the ways of treating anaemia in people with chronic kidney disease is by ESA injections, although you will usually hear the injections referred to as EPO injections.

You should be offered an ESA if it is likely to benefit you (some people's medical problems mean they wouldn't receive any benefit from ESA treatment). The decision about whether to offer you an ESA should be based on whether the treatment would be suitable for you, regardless of your age.

There are different ESAs available, and your anaemia specialist should try to find the one that will suit you best. They should explain the differences between the ESAs, and discuss whether you want to inject them 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, how to store ESAs at your home and the different ways they are supplied (for example, whether you collect them from your hospital or whether they are delivered to your home). This should be agreed with you and recorded in a care plan, and the plan should be reviewed if your needs or preferences change. If you are taking an ESA

it is important that your blood pressure is checked regularly (see the box below on information and support).

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 might help you. Your anaemia specialist should discuss with you (and your carers, if appropriate) the pros and cons of having ESA treatment for a trial period.

The box below gives details of the information you should have if you're considering ESA treatment.

Information and support you should have if you're thinking about having 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 why it is important to take the ESAs as directed.
- Arrangements should be made so that you can obtain your ESA supply as easily as possible if you are going to inject it yourself.

Continuing with ESAs

Your anaemia specialist should check and discuss with you how the ESA treatment is going, and whether you should continue with the same ESA or change to a different one. It may be necessary to adjust your dose and how often you have an injection to keep your haemoglobin levels stable. Haemoglobin is needed to transport oxygen around the body in red blood cells. If your haemoglobin level changes unexpectedly, you should be offered tests to find the reason for this so that it can be treated. (See [checking whether your treatment is working](#).)

If you are having ESA treatment for a trial period you, your family (or carers) and your anaemia specialist should discuss how the trial went and agree whether to continue or stop the ESA treatment.

Questions to ask about treatment

- Can you tell me why you have decided to offer me this particular type of treatment?

- What are the pros and cons of having 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 or side effects associated with this treatment?
- What if I don't want the treatment? What are my options other than the recommended treatment?
- Is there some written information about the treatment I could have?
- How will I feel after the treatment?
- Will the treatment hurt?
- How often will I need to have the treatment?
- Can I take something from my chemist or health food shop?
- Can I talk to other patients about my treatment options?

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 anaemia specialist should think about whether treating it would help your anaemia, and discuss this with you.

Checking whether your treatment is working

The box below gives information about the blood tests you might need to have to check whether your treatment is working, and your specialist should discuss with you what test results would be ideal for you (these are called target levels). How often you have these tests will depend on your treatment and how severe your anaemia is.

Tests for checking if your anaemia treatment is working

Blood test	When you should have it	Target levels
Haemoglobin (Hb) 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 anaemia specialist should discuss where this is done so that it is as convenient for you as possible</p>	<ul style="list-style-type: none"> • All people aged 2 years and over: 100 to 120 g per litre • Children under 2 years: 95 to 115 g per litre
Percentage of hypochromic red cells, reticulocyte haemoglobin content	<ul style="list-style-type: none"> • Every 3 months • Every 1–3 months if you are receiving haemodialysis^a 	<ul style="list-style-type: none"> • Hypochromic red cells: less than 6% (if you are on ESAs) • Reticulocyte haemoglobin content: more than 29 picograms
Below are the tests offered if 'percentage of hypochromic red cells' and 'reticulocyte haemoglobin content' are not available		
Serum ferritin (if you are receiving iron) and transferrin saturation	<ul style="list-style-type: none"> • Not within 1 week of having an iron infusion^b 	
	<ul style="list-style-type: none"> • Serum ferritin every 1–3 months 	<ul style="list-style-type: none"> • Serum ferritin: more than 100 micrograms per litre

	<ul style="list-style-type: none"> • Transferrin saturation <ul style="list-style-type: none"> - Every 1–3 months if you are receiving haemodialysis - Every 3 months if you are going to have a kidney transplant before dialysis, or you are receiving peritoneal dialysis^c 	<ul style="list-style-type: none"> • Transferrin saturation: more than 20%
<p>^a Haemodialysis or kidney dialysis – a procedure to remove fluid and waste products from the blood.</p> <p>^b Iron injection given using a drip or a machine.</p> <p>^c Peritoneal dialysis uses the patient's peritoneum (the thin membrane lining the inside of the abdomen) as a filter.</p>		

If ESAs aren't working

Some people continue to have low numbers of red blood cells despite having ESA treatment. This means there is less haemoglobin to carry oxygen around the body in the red blood cells. These people might need to continue on high doses of ESA to stay at their target haemoglobin level or if their haemoglobin level is low. If this happens to you, your anaemia specialist should try to find out what is causing it (for example, it might be happening because you're losing blood or there's another medical problem). If your doctor can't find anything else that could be causing it, the problem could be because of your kidney disease or the ESA treatment itself. Your anaemia specialist should discuss any other tests and treatment that might be needed if this seems to be the case.

Your doctor may refer you to a service that specialises in treating blood conditions to investigate why the ESAs aren't working. They are more likely to do this if they think you might have a blood disorder. Once you have been referred, one of the possible treatment options may be a blood transfusion. But before deciding whether to offer you a transfusion your doctor should take into account your symptoms, quality of life and what other conditions you have. They should discuss the risks and benefits of transfusion with you (or your family or carers, if appropriate).

If your ESAs aren't working and you are having regular transfusions, your anaemia specialist may ask you if you would like to stop your ESA treatment for a while to see if you still need it. After

stopping the ESA, your anaemia specialist should check after 1 to 3 months to see if you need to go back onto ESA treatment.

Questions to ask about transfusions

- What might a blood transfusion mean for me?
- Why might I need a transfusion?
- What are the risks of having a transfusion?
- Are there any reasons why I shouldn't have a transfusion?
- What are the advantages and disadvantages of having a transfusion?

Treatments not recommended for anaemia

The following treatments have not been shown to give extra benefit for treating anaemia in people who have chronic kidney disease, and you should not be offered them to treat anaemia. However, 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.

Terms explained

Off-label

In the UK, medicines are licensed to show that they work well enough and are safe enough to be used for specific conditions and groups of people. Some medicines can also be helpful for conditions or people they are not specifically for. This is called 'off-label' use. Off-label use might also mean the medicine is taken at a different dose or in a different way to the licence, such as using a cream or taking a tablet. There is more information about licensing medicines on [NHS Choices](#).

Sources of advice and support

- British Kidney Patient Association, 01420 541424
www.britishkidney-pa.co.uk
- Kidney Research UK, 0845 070 7601
www.kidneyresearchuk.org
- Kids Kidney Research
www.kidskidneyresearch.org
- National Kidney Federation, 0845 601 0209
www.kidney.org.uk
- Polycystic Kidney Disease Charity, 0300 111 1234
pkdcharity.org.uk

You can also go to [NHS Choices](#) for more information.

NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

ISBN: 978-1-4731-1150-9

Accreditation

