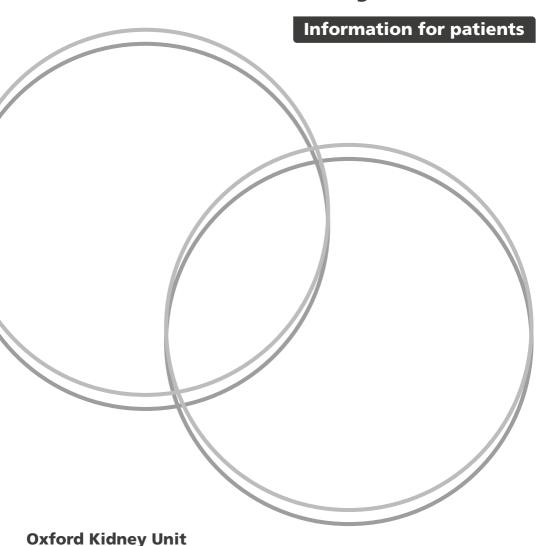


Erythropoietin therapy in people with chronic kidney disease



You have been given this leaflet because you have been told that you need to start erythropoietin (EPO) treatment. If you have questions after reading this leaflet please speak to your kidney doctor or the renal anaemia team.

Anaemia is common in people with chronic kidney disease (CKD), after kidney transplantation and when prescribed certain drugs such as chemotherapy.

Anaemia can make you feel tired, breathless, sleepy, exhausted, forgetful and more prone to feeling the cold. You may find it difficult to do the usual activities that you normally do.

Anaemia is when your haemoglobin level is low because there are fewer red blood cells. Haemoglobin is a protein in red blood cells that carries oxygen around the body.

We measure the haemoglobin by taking a small blood test called a full blood count (FBC). We also measure iron levels (ferritin and transferrin saturation), as an adequate supply of iron is required for the production of haemoglobin.

What should the levels be?

The target haemoglobin (Hb) level for people with CKD should be between 100 and 120 grams/L.

Your ferritin level range should be between to 200 and 500 and the transferrin saturation (TSAT) greater than 20%. However if you're on dialysis the range may vary. Please speak to your kidney team for further information.

What is erythropoietin?

Erythropoietin is a hormone made by the kidneys. It works by signalling bone marrow to produce more red blood cells. If your kidney function is poor your body is unable to make sufficient erythropoietin.

Most people refer to erythropoietin as EPO or an erythropoietin stimulating agent (ESA). Erythropoietin is only available as an injection. The injections need to be stored in a refrigerator (do not freeze it). Before you start the injection we will teach you or a carer how to administer the injection.

There are different preparations of EPO. These include:

- Retacrit (epoetin zeta)
- Eprex (epoetin alfa)
- Aranesp (darbepoetin alfa)

These preparations work in the same way, but some provide longer effects than the others. The renal anaemia team will select the suitable preparation to match your needs.

EPO is injected under your skin (subcutaneously) in the abdomen (not near the navel) or the outer part of the thigh. If you are on haemodialysis the injection can be given into the dialysis machine.

How do I use the injection?

- Take an injection out of the refrigerator 15 minutes before you are going to use it, this ensures it is at room temperature and will reduce discomfort when you are administering the injection.
- Check the injection to make sure it is the right dose, has not passed its expiry date, is not damaged and the liquid is clear.
- Choose an injection site. Alternate your injection site as this will give you better absorption.
- Wash your hands and injection site using soap and water.
- Hold the injection by the body with the covered needle, take the cover off by holding the barrel and pulling the cover off carefully, don't twist it.
- With the free hand pinch a fold of skin between your thumb and index finger.
- Push the needle into the fold of skin.
- Push the plunger with your thumb as far as it will go so that you inject all of the liquid.
- Slowly withdraw the syringe and discard it in the sharps bin container.
- There might be a little bleeding at the injection site when the needle is removed from the skin. This is normal, apply a small amount of pressure at the site for about a minute.

What side effects might I experience?

Frequency

Very common

(about 1 in 10 people)

Signs and/or symptoms

Diarrhoea, nausea, vomiting, fever

Frequency

Common

(about 1 in 100 people)

Signs and/or symptoms

- High blood pressure, up to 30% of people have a rise in their blood pressure at the beginning of this treatment
- Headache
- Allergic reaction, including a rash
- Flu-like symptoms
- Aching joints and muscles
- Pain at the injection site

Please let the renal anaemia team know if you experience any of these side effects

Frequency

Rare (about 1 in 1,000 people)

The anaemia team will check your blood results to make sure this isn't happening

Signs and/or symptoms

 Pure red cell aplasia – this refers to a type of anaemia which the bone marrow stops making red blood cells

Important information

Please measure your blood pressure once a week for 12 weeks.

If your diastolic blood pressure (bottom/2nd number on BP machine display) is above 100 mmHg or higher do not administer the injection. Please contact the anaemia team on page 6.

How will the anaemia team monitor me when having this therapy?

You will need a blood test taken monthly (full blood count and iron level) when you first start the treatment and then every two months. This can be arranged at the Renal unit, your GP surgery, or home phlebotomy, if applicable.

How will I get EPO?

A company will deliver the injections directly to your home. The first delivery will consist of two months' supply, followed by 4 monthly deliveries.

What will I receive on my first delivery?

- EPO injections
- A specific bin to put the used injections in after you have had the injection called a sharps bin.

How do I contact the Anaemia Team?

The anaemia team work Monday (not bank holidays) to Friday 8am to 6pm. If they are not available in working hours please call the mobile number.

 Stoke Mandeville, High Wycombe:
 01865 225 348

 Swindon:
 01793 605 291

 Milton Keynes:
 01908 996 489

 Banbury:
 01865 225 349

 Oxford:
 01865 228 921

 Mobile:
 07385 933 254

Polarspeed: **08007 833 178** (Option 1)

Useful websites

Oxford Kidney Unit

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

Website: www.ouh.nhs.uk/oku

Kidney Patient Guide

Information for patients with kidney failure and those who are for them.

Website: www.kidneypatientguide.org.uk

Kidney Care UK

A charity which has lots of practical support and information for people with kidney disease.

Website: www.kidneycareuk.org

Six Counties Kidney Patients Association

The SCKPA is run for patients by patients or family members.

They offer support to people suffering from kidney disease or who are on dialysis. They work closely with the Oxford Kidney Unit and have branches in Oxfordshire, Northamptonshire, Buckinghamshire, and Milton Keynes, and parts of Wiltshire, Gloucestershire and Berkshire.

Website: www.sixcountieskpa.org.uk

OUH Patient Portal Health for Me

Please ask a member of the kidney team to sign you up to the patient portal.

Website: <u>www.ouh.nhs.uk/patient-guide/patient-portal</u>

Further information

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

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

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

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

Authors: Csaba Kiss, Senior Anaemia Specialist Nurse Chen Tseng, Specialist Renal Pharmacist

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charity@ouh.nhs.uk | 01865 743 444 | hospitalcharity.co.uk

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