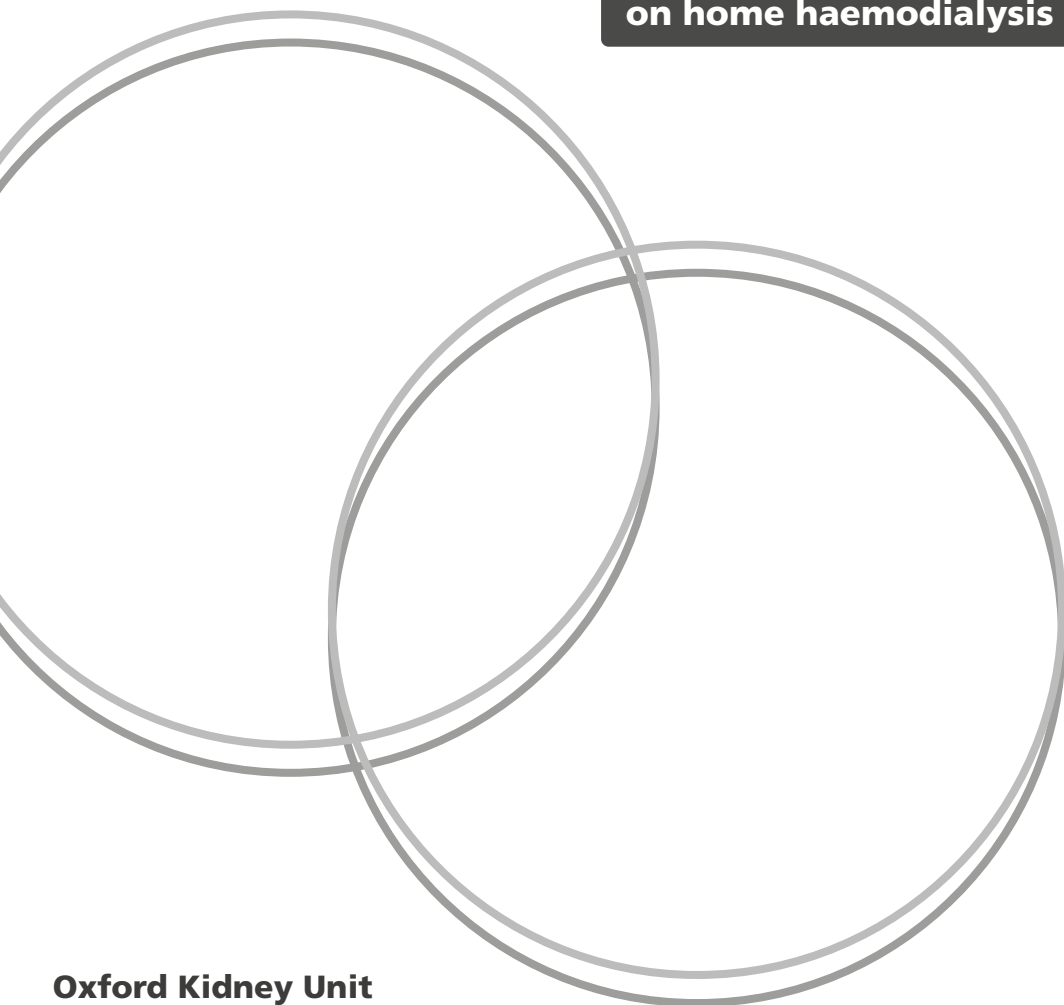


Intravenous iron treatment at home for people with kidney disease

**Information for people
on home haemodialysis**



If you are a home haemodialysis patient and you need to have intravenous (IV) iron treatment, then this leaflet is for you. This leaflet will help you to decide whether to have your iron treatment in hospital or at home.

Why do I need iron?

Iron is an essential mineral for your body. It is needed for the production of haemoglobin, which is a vital ingredient in red blood cells. Haemoglobin is very important, as it carries oxygen from your lungs to the rest of your body.

Your body normally absorbs iron from food. As you have kidney disease, your body may not be able to absorb enough iron from food. If you do not have enough iron in your body, you may not make enough red blood cells. This is known as 'iron deficiency anaemia'.

What happens if I have low iron levels?

If your iron level is low you may experience the following symptoms:

- tiredness
- weakness
- shortness of breath
- pale skin
- headache
- heart palpitations (noticeable heartbeats)
- brittle nails.

How are my iron levels measured?

Your body stores iron by attaching it to proteins. The most important of these proteins is called ferritin. A low ferritin level usually indicates low iron levels.

Your kidney doctor or nurse will check your iron levels by taking a small blood sample to measure the amount of ferritin that is in your blood. If your ferritin is below 700µg/L (micrograms per litre) you may need iron treatment.

How are low iron levels treated?

Iron can be given as tablets, but these can cause constipation and are not absorbed very well when you have kidney disease. Most people on haemodialysis will need intravenous (IV) iron. This is a liquid solution which contains iron and is given as an injection into a vein. It can be given either through a butterfly needle (a small needle), a cannula (a small plastic tube), or while you are on the haemodialysis machine.

Are there any risks?

There has been an alert from the MHRA (Medicines and Healthcare Products Regulatory Agency) about the use of intravenous iron. The MHRA are a Department of Health body that advises about the safe use of medicines and other healthcare products.

The MHRA were concerned about the risk of a severe allergic reaction (called anaphylaxis) which can happen when IV iron is being given. However, if the reaction is severe it could be life threatening.

For this reason it is important that you understand the potential risk if you are going to have this treatment at home. If you decide to have iron treatment at home you will need to speak with your kidney consultant. Your kidney consultant will discuss this small risk with you. If you decide to have treatment at home we will document this on your electronic patient record. This ensures everyone involved in your care is aware you are receiving intravenous iron at home.

Are there any situations when I would not be able to have home IV iron?

You will not be able to have intravenous iron at home if you have the following:

- Previous hypersensitivity reaction to any IV iron preparation.
- Non-iron deficiency anaemia (e.g. haemolytic anaemia).
- Iron overload or disturbances in utilisation of iron (e.g. haemochromatosis, hemosiderosis).
- Hypersensitivity to the active substance, to Diafer or any of its excipients.
- Known serious hypersensitivity to other parenteral iron products.
- Decompensated liver cirrhosis and hepatitis.

If any of these affect you, your kidney consultant will talk with you about treatment options.

What are the choices for IV iron?

You will be asked to decide whether you want to have your IV iron in hospital or at home:

Option 1: IV iron treatment at home

You could opt to give yourself an IV iron product called Ferric Derisomaltose (Diafer) during your dialysis at home. This usually needs to be given once every two weeks. Your dialysis nurse will teach you how to give yourself Ferric Derisomaltose (Diafer), by injecting it into the venous chamber of your dialysis machine during the first 2 hours of haemodialysis. You will need to have had a minimum of 2 or more doses in the hospital with no complications before you can administer iron at home.

Before starting this treatment you would need training on how to use an EpiPen, in the very unlikely event that you have a serious allergic reaction to the treatment. An EpiPen contains adrenaline, which is the emergency treatment for a severe allergic reaction (anaphylaxis).

Your home haemodialysis nurse will arrange 2 EpiPen's for you to take home. It is very important that you let your nurse know when they are due to expire so they can organise a replacement. Please give your nurse at least 1 month's notice.

You will also need to keep a poster on your haemodialysis machine that tells you about anaphylaxis and what to do in an emergency.

Your EpiPen's must be kept next to your haemodialysis machine.

Make sure you tell the people who live with you too.

Option 2: IV iron treatment in hospital, administered by a nurse

You could opt to have an alternative IV iron product called Monofer or Ferinject when you come to your routine clinic appointment with your kidney doctor.

The IV iron is injected into a vein in the back of your hand, either through a butterfly needle (a small needle) or a cannula (a small plastic tube). It can also be given through your dialysis line or fistula (although you will not actually have dialysis at that appointment).

It takes about 20 minutes for the dose of iron to be given, but you will need to be in the department (Renal Day Case Unit or your local Haemodialysis Unit) for 30 minutes after administration, in case you have a reaction to the IV iron.

Your home dialysis nurse could organise for you to have this treatment alongside your regular visits. You are likely to need it two or three times a year.

Option 3: persist with oral iron supplementation

This is not generally recommended, but is still a choice.

Side effects

Most people do not experience any problems, but there are some side effects you should be aware of:

	Symptoms	Treatment
Common (about 1 in 10 people)	<ul style="list-style-type: none"> • Headache • dizziness • flushing • high blood pressure • feeling sick (nausea). 	Your treatment will be stopped for a short period and then restarted at a slower rate. If the side effects continue, the infusion will be discontinued.
Uncommon (about 1 in 100 people)	<ul style="list-style-type: none"> • Change in taste sensation • low blood pressure • vomiting • tingling sensation • constipation or diarrhoea • rash • fatigue • high temperature. 	Your nurse will stop the treatment and will ask a doctor to see you. You will be prescribed some medication to ease the symptoms. We may suggest another type of iron treatment instead.
Rare (less than 1 in 1,000 people)	<ul style="list-style-type: none"> • Flu-like illness (may occur a few hours to several days after the treatment) • swelling of the face • difficulty breathing • fainting. 	Your nurse will stop the iron infusion and give you emergency treatment for anaphylaxis.

Who can I speak to for more information?

Your local Haemodialysis Unit or Kidney Doctor will be happy to answer any questions you might have.

Useful telephone numbers for the Haemodialysis Units:

Stoke Mandeville	01296 316 997
High Wycombe	01494 426 347
Swindon	01793 605 286
Milton Keynes	01908 996 494
Banbury	01295 229 811
Oxford	01865 225 695
Whitehouse Dialysis Unit	01295 228 552 or 01295 228 553

If you have an appointment to have an iron injection in Oxford, please call the Renal Day Case Unit:

Telephone: 01865 226 106

Useful websites

GOV.UK

This website also has further information about intravenous iron.
Website: www.gov.uk/drug-safety-update/intravenous-iron-and-serious-hypersensitivity-reactions-strengthened-recommendations

National Kidney Foundation

This website has information about iron deficiency anaemia.
Website: www.kidney.org/atoz/content/ironDialysis

Oxford Kidney Unit

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

Website: www.ouh.nhs.uk/oku

Kidney Care UK

This website provides information and support for kidney patients and their family.

Website: www.kidneycareuk.org/about-kidney-health/conditions/anaemia

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 renal team to sign you up to the patient portal.

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

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.

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