

Clinical haematology

Deferiprone tablets

Information for patients, relatives and carers

Introduction

This leaflet explains how and when to take deferiprone tablets. If you have any questions about the information below, please speak to your haematology doctor or clinical nurse specialist.

What is deferiprone?

Frequent blood transfusions are given to patients with different blood disorders such as sickle cell disease and thalassaemia. This can lead to an excess of iron building up in major organs, causing iron overload. If left untreated, this can cause complications to the heart, liver and endocrine glands (adrenal and pancreas) and may lead to irreversible damage to these organs.

Deferiprone is an iron-chelating medicine used to remove excess iron from the body. It does this by binding to iron in the blood, which is then passed out in the urine. It is used to chelate iron in thalassaemia major patients who have been unable to tolerate other iron chelators or in patients who need combination therapy with deferoxamine.

How and when to take deferiprone

Deferiprone must be taken three times a day, with the first dose in the morning, second dose at lunchtime and the third dose in the evening:

- it is taken by mouth in tablet form and comes in 500mg and 1000mg tablets
- it can be taken with or without food
- allow at least a four-hour interval between taking deferiprone and taking other medications or supplements containing aluminium or zinc
- if you find it difficult remembering to take your medication on time, it is a clever idea to set yourself a reminder on your mobile phone or alarm clock. This will help you to get into a routine

What if I miss a dose?

Take your medication as soon as you remember. Deferiprone will be most effective if you do not miss any doses. If it is too close to your next dose, then miss it and take your usual dose as normal. Do not take double the dose to make up for a missed one.

The risks and side effects of taking deferiprone

Most medicines may cause unwanted side effects, but not everyone will get them. These side effects will usually ease as the body adjusts to the medicine. They include:

- feeling sick (nauseated), tummy (abdominal) pain, runny poo (diarrhoea). These symptoms gradually reduce and usually go away after a few weeks.
- your urine being reddish brown in colour, though this is harmless and will not cause any problems
- increase in appetite, headaches and feeling tired
- painful or swollen joints which may indicate signs of arthritis. Your doctor will advise you on how to manage this, that is by reducing the dose, stopping the drug or treating with arthritis medication
- needing additional supplements of vitamin C and zinc

Taking deferiprone can also cause a fall in your white blood cell count. One type of white blood cell, called a neutrophil, is important for fighting bacterial infections.

- A low neutrophil count (called neutropenia) may put you at risk of developing serious infection. Neutropenia is quite common with deferiprone and around 4% of patients may have a low neutrophil count occasionally.
- If the low neutrophil count continues to fall, it can become a serious problem. Severe neutropenia is known as agranulocytosis (1% of patients may get this). Agranulocytosis puts you at risk of developing serious infections that can be fatal unless quickly identified and treated.
- So, it is especially important that you have weekly blood tests to check the neutrophil count while taking deferiprone. If you develop neutropenia, your healthcare professional should check your blood counts every day until your white blood cell count improves

Liver function tests should be measured monthly

If you experience any of the following symptoms, stop your treatment and call the renal haematology triage unit (RHTU) on **0203 311 7755**. Explain your symptoms and say that you've been taking deferiprone:

- you develop a high temperature over 38°C or signs of infection such as a sore throat or flu-like symptoms
- you develop abdominal pain, fever, diarrhoea and vomiting as these may indicate an infection caused by bacteria called Yersinia

Reasons why regular monitoring is important

The outpatient clinic is the best place for monitoring your health condition. Working in partnership with you helps the red cell team in the early detection and management of potential complications by:

- assessing how well the treatment is working
- reviewing and amending the dose of the medication as required for maximum benefit
- helping you to understand and manage your health and well-being

Alternatives to deferiprone

Your doctor will decide which iron chelator will be appropriate for you to take. There are other iron chelators, deferasirox (Exjade®) and desferrioxamine (Desferal®) that may be a suitable alternative. However, this depends on your overall health and any underlying issues you may have.

Deferiprone is often used as a single chelation treatment or as part of a combination treatment with desferrioxamine.

How to store deferiprone

- Keep it out of sight and reach of children
- Store it in a cool dry place away from direct sunlight and heat

Getting the most from your treatment

- Always take your medication as instructed by your doctor. The box will be labelled with instructions for how to take it. If you are unsure, you can always speak to the pharmacist, your doctor or your clinical nurse specialist (CNS).
- When you first start, you will need to have weekly blood tests to monitor your full blood count and kidney function. Once stabilised, blood tests are usually taken monthly.
- If you become unwell with an infection the treatment will stop until you have recovered.
- You must use effective contraception while you are taking deferiprone. Discuss with your doctor which method is best for you.
- It is advisable not to become pregnant while taking deferiprone as it can harm the baby. If you plan to become pregnant, discuss it with your doctor so that appropriate arrangements can be made.

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- If you do become pregnant while taking deferiprone, stop taking it and contact the CNS or your doctor. An early clinic appointment to see the doctor will be arranged.
 - Do not use deferiprone if you are breastfeeding as the drug may be harmful to the baby.
 - Try to attend all your clinic appointments as well as your blood tests and scans. If you are unable to attend, you can call the number on your appointment letter to reschedule to a time that is convenient for you.
 - Do not throw away any medicines down your toilet or in your household waste. Return medicines you no longer use to your pharmacist who will dispose of them in the correct manner. These measures will help protect the environment.

For further information

Call the CNS for haemoglobinopathies and iron overload on **020 3313 8553**

OR

Call the hospital switchboard on **020 3313 1000** and ask for the RHTU or red cell registrar/consultant on call

Alternatively, when you attend your clinic appointment you can discuss your concerns with your doctor or CNS.

How do I make a comment about my visit?

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. If you have any **suggestions** or **comments** about your visit, please either speak to a member of staff or contact the patient advice and liaison service (**PALS**) on **020 3313 0088** (Charing Cross, Hammersmith and Queen Charlotte's & Chelsea hospitals), or **020 3312 7777** (St Mary's and Western Eye hospitals). You can also email PALS at imperial.pals@nhs.net The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

Alternatively, you may wish to complain by contacting our complaints department:

Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street
London W2 1NY

Email: ICHC-tr.Complaints@nhs.net

Telephone: **020 3312 1337 / 1349**

Alternative formats

This leaflet can be provided on request in large print or easy read, as a sound recording, in Braille or in alternative languages. Please email the communications team:
imperial.communications@nhs.net

Wi-fi

Wi-fi is available at our Trust. For more information visit our website: www.imperial.nhs.uk

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