

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 (CNS).

What is deferiprone?

Frequent blood transfusions are given to patients with different blood disorders such as sickle cell disease and thalassemia. This can lead to an excess of iron accumulation 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 desferrioxamine.

How and when to take deferiprone

Deferiprone must be taken three times a day with the first dose in the morning, second dose at lunch time 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 good 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.

What are 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:

- feeling sick (nauseated), tummy (abdominal) pain, runny poo (diarrhoea). These symptoms gradually reduce and usually go away after a few weeks
- your urine will be reddish brown in colour but 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, i.e. reduce the dose, stop the drug or treat with arthritis medication
- you may need additional supplements of vitamin C and zinc
- your white blood cell count may fall. One type of white blood cell, called a neutrophil, is important for fighting bacterial infections. If you have a low neutrophil count (called neutropenia) you may be at risk of developing serious infection. Neutropenia is quite common with deferiprone and around 4 per cent 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 per cent of patients may get this) and if you develop agranulocytosis, you will be at risk of developing serious infections that can be fatal unless quickly identified and treated
- it is very 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 **020 3313 1255** explaining your symptoms and 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 wellbeing

Are there any alternatives to this medication?

Your doctor will make the decision as to which iron chelator will be appropriate for you to take. There are other iron chelators, such as 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 the 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 of how to take it. If you are unsure you can always speak to the pharmacist, your doctor or your 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 whilst 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
- If you do become pregnant whilst taking deferiprone, stop taking it and contact your CNS or 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 of 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 for a time that is convenient for you
- Do not throw away any medicines via your toilet or 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 4655**

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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