Iron Chelation Therapy

Information for patients and families

Read this information to learn:

- why you may have too much iron in your body
- why it is important to treat this problem
- how iron chelation therapy can help
- what to do during iron chelation therapy





Why would I have too much iron in my body?

It is normal for you to have iron in your body. Your body uses iron to help make hemoglobin. Hemoglobin is a protein that carries oxygen in your blood. But sometimes, you may have too much iron in your body.

There are 2 main reasons why you have too much iron in your body:

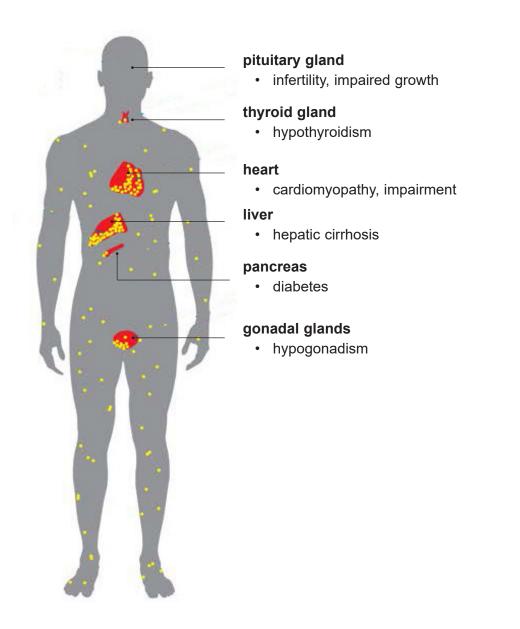
- 1. Your body absorbs too much iron from the food you eat. This problem may run in your family.
- 2. You have had repeated red blood cell transfusions.

For example, you may have too much iron in your body if you have had more than 20 units of blood to treat medical problems such as:

- thalassemia
- sickle cell disease
- chronic anemia

What can happen if I have too much iron in my body?

Having too much iron in your body can affect your endocrine system, liver, heart or all three. The picture below shows the what problems may happen in different parts of the body.



Iron chelation therapy helps remove extra iron from your body.

What is iron chelation therapy?

During iron chelation (pronounced Kee-LAY-shun) therapy, you take medicines called iron chelating agents to help remove extra iron from your body.

- Iron chelating agents stick to the iron in your blood
- and help your body get rid of the iron easier.
- The extra iron leaves your body in your urine (pee) or feces (poo). Your pee will turn slightly red because of the medicine and iron in it.

Your doctor may recommend iron chelation therapy after talking to you about your medical history and after you have tests. The tests will show how much iron is in your organs and body tissues.

What kinds of tests will I need to have?

Your doctor may order different tests to find out how much iron is in your body.

Your doctor will talk with you about which tests are right for you.

These tests may include:

- Blood tests to check your ferritin level. Your ferritin level measures how much iron is in your blood. Many other things can affect your ferritin level, such as a recent illness or liver inflammation.
- Every year, you may have an MRI (magnetic resonance imaging) scan to see how much iron is in your liver, heart and other organs. This helps your team check how you are doing with your chelation therapy.
- You may need a liver biopsy if you cannot have an MRI. You have a liver biopsy in the hospital. During a biopsy, your doctor will carefully take out a very small piece of your liver. This small piece is sent to a lab to check how much iron is in it.

What kinds of iron chelating agents may I need to take?

There are a few different kinds of chelating agents. You may need more than 1 at the same time.

Name of chelating agent	How do I take it?	What are the possible side effects?	How are side effects monitored?
Deferasirox (Exjade®, Jadenu®, Type J®)	by mouth	 rash upset stomach (diarrhea, nausea, vomiting or both) damage to kidneys, liver, or both 	 monthly urinalysis creatinine liver enzymes ferritin checked every 3 months
Deferoxamine (Desferal®)	needle put in just below your skin, or needle put into your vein	 hearing or vision problems pain at needle site low blood pressure fast, abnormal heartbeat 	• ferritin checked every month
Deferiprone (Ferriprox®)	by mouth	 upset stomach (nausea or vomiting) joint pain increased risk of getting infections 	 complete blood count every week ferritin checked every 3 months

What should I do when I am getting iron chelation therapy?

- Ask for your latest iron (ferritin) level when you see your doctor, and write it down. This will help you keep track of how well your therapy is working. Writing down the results of your liver and heart MRI will also help you keep track.
- Always follow the instructions your doctor or nurse practitioner gave you for taking your chelating agent(s).
- Tell your doctor or nurse practitioner if you have any side effects from your iron chelation therapy. Your doctor or nurse practitioner will give you instructions about how to manage the side effects.

Who can I contact?

The Red Blood Cell Disorders Clinic

7th Floor – Norman Urquhart (NU) Building Toronto General Hospital, UHN 200 Elizabeth Street, Toronto, ON M5G 2C4 Phone: 416 340 4882 | Fax: 416 340 4559

Your RBCD Clinical Team

Dr. Richard Ward – Medical Director Dr. Kevin Kuo – Hematologist Dr. Jacob Pendergrast – Hematologist Sinthu Srikanthan – Social Worker Colleen Johnson – Nurse Practitioner Hasumie Hosogoe – Nurse Practitioner Omar Florez – Administrative Assistant Vanessa Loiacono – Manager

Patient Relations

Please speak to your health care team for questions or concerns. Call the Patient Relations team if you need more help.

To speak with a Patient Relations team member: Phone: 416 340 4807 Email: <u>patientrelations@uhn.ca</u>



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