ARTHRITIS
INFORMATION SHEET

Haemochromatosis and haemochromatotic arthritis

This sheet has been written for people with joint pain and damage resulting from haemochromatosis. It provides general information to help you understand how you may be affected and what you can do to manage it. Further sources of information and advice are also listed.

What is haemochromatosis?

Haemochromatosis is a condition caused by a build up of iron in your body. People with haemochromatosis absorb too much iron from food (iron overload) and the extra iron can damage organs, particularly the liver, heart, pancreas, bones and joints.

What are the symptoms?

The symptoms of haemochromatosis can vary from person to person. Early haemochromatosis often has no symptoms. As iron slowly builds up in the body over many years, symptoms may begin to be noticed, usually after the age of 40. Symptoms of haemochromatosis can include:

- fatigue (tiredness)
- abdominal pain
- symptoms of diabetes
- joint pain, and possibly joint swelling. This occurs most commonly in the joints of the fingers and hands. The wrists, elbows, hips, knees, ankles and joints in the feet can also be affected.

Over time, more serious complications and symptoms of untreated iron overload can occur. This can include liver damage, poor heart function, diabetes, joint damage (similar to osteoarthritis), loss of libido (sex drive) and osteoporosis (thinning of the bones). However not all people with haemochromatosis will experience these complications. For example, only one in four people will have joint damage.

What causes it?

Haemochromatosis results from a defect (mutation) in a single gene known as the HFE gene. This gene controls the amount of iron your body absorbs from food. You can develop haemochromatosis if you inherit a defective HFE gene from both your mother and father.

How is it diagnosed?

Haemochromatosis is usually diagnosed by simple blood tests called complete iron studies. It may also be confirmed with a blood test for the faulty HFE gene.

What will happen to me?

With early diagnosis and treatment, before complications occur, most people with haemochromatosis can lead full and active lives. If haemochromatosis is untreated, it can lead to a number of complications, especially in your joints and in organs where excess iron tends to be stored (liver, heart, pancreas). Joint damage from haemochromatosis does not tend to disappear, even if iron levels return to normal with treatment. People with joint damage often have ongoing pain, stiffness and difficulties using their joints. This usually requires treatments such as medicines, physiotherapy, aids/gadgets and lifestyle changes. Arthritis caused by haemochromatosis rarely causes severe disability but, when it does, surgery to replace joints may be necessary.

Can haemochromatosis be cured?

At present there is no cure for haemochromatosis or the arthritis caused by iron overload. Early diagnosis and treatment is aimed at reducing the long term complications of the condition.

What treatments are there?

The goal of treatment for haemochromatosis is to reduce iron levels to a safe level and prevent long term complications of iron overload. Treatment for haemochromatosis usually involves removal of blood via a needle into the arm, similar to blood donation. Approximately 450mL of blood is removed at regular intervals until iron levels are at a safe level.

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1800 011 041 www.arthritisaustralia.com.au

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Although this type of treatment is usually very effective for iron levels, it does not appear to reduce the symptoms of arthritis or reverse the damage to the joints.

Treatments for arthritis vary depending on which joints are affected and can include:

- pain relief, using medicines such as paracetamol
- non-steroidal anti-inflammatory drugs (NSAIDs), including topical creams and ointments
- an exercise program tailored to your needs and ability
- a weight loss program, if you are overweight
- joint replacement surgery, if your symptoms are no longer controlled with other therapies.

Your local Arthritis Office has information sheets on medicines, physical activity, healthy eating and surgery.

What can I do?

See your doctor for treatment and advice.

If a family member has been diagnosed with haemochromatosis, ask your doctor whether you should have a genetic test for this disease. Remember that the earlier it is diagnosed, the greater the likelihood that serious complications can be prevented. If you have been given the diagnosis yourself, ask your doctor which complications have already been identified and whether any others need to be looked for. If some complications have been identified, is the current treatment optimal for minimising progression and potential problems in the future?

Learn about haemochromatosis and play an active role in your treatment.

Learn as much as you can about the disease and how it behaves. Not all information you read or hear is trustworthy so always talk to your doctor or healthcare team about treatments you are thinking about trying. Reliable sources of information are also listed in the section below.

Learn ways to manage your arthritis pain.

See the *Dealing with pain* information sheet.

Stay active.

Exercise is strongly recommended for people with arthritis. You may find it useful to see a physiotherapist or exercise physiologist for advice. See the *Physical activity* information sheet.

Have a healthy diet and manage your weight.

There is no diet that can cure arthritis but a well-balanced diet will help you reach and keep to a healthy weight. Losing any extra body weight will reduce the strain on sore joints in your legs, feet and back. See the *Healthy eating* information sheet.

Balance your life.

Learn about gadgets that make daily tasks easier and how to balance rest and activity. See the *Saving energy* information sheet.

Acknowledge your feelings and seek support.

Living with pain and arthritis can be overwhelming and it is natural to feel scared, frustrated, sad and sometimes angry. Be aware of these feelings and get help if they start affecting your daily life. See the *Arthritis and emotions* information sheet.

CONTACT YOUR LOCAL ARTHRITIS OFFICE FOR MORE INFORMATION SHEETS ON ARTHRITIS.

Learn about haemochromatosis and your treatment options. There are many things you can do to manage pain and other symptoms.

This sheet was produced in association with Haemochromatosis Australia.

Haemochromatosis Australia
Inherited Iron overload disorder

For more information:

Haemochromatosis Australia have a booklet titled *Haemochromatosis: Your Questions Answered* available by calling the InfoLine on 1300 019 028 or downloading from **www.ha.org.au**

Websites: Arthritis Research UK **www.arthritisresearchuk.org**
Australian Rheumatology Association – information about medicines and seeing a rheumatologist (arthritis specialist) **www.rheumatology.org.au**

 Source: A full list of the references used to compile this sheet is available from your local Arthritis Office.