This information sheet has been produced by the Australian Rheumatology Association to help you understand the medicine that has been prescribed for you. It includes important information about:

- how you should take your medicine
- what are the possible side effects
- what tests you must have to monitor your condition and to detect unwanted effects
- other precautions you should take.

Please read it carefully and discuss it with your doctor.

Important things to remember

- While taking d-penicillamine you should see your rheumatologist regularly to make sure the treatment is working and to minimise any possible side effects.
- You should have regular blood and urine tests as directed by your rheumatologist.
- If you are concerned about any side effects you should contact your rheumatologist as soon as possible.

What is d-penicillamine?

D-Penicillamine, usually referred to as penicillamine, (brand name: D-Penamine) is a medicine used to treat rheumatoid arthritis. Occasionally it is used to treat other rheumatic diseases such as scleroderma.

Penicillamine should not be confused with the antibiotic penicillin, which is a different compound. Those who are allergic to penicillin may not necessarily be sensitive to penicillamine.

Penicillamine is an immunosuppressive medicine, which means that it works by reducing the activity of the immune system.

In rheumatoid arthritis this action helps to reduce inflammation and thus reduce pain and swelling. It also limits damage to the joints and helps to prevent disability in the long term. Because penicillamine reduces the damage to the joints, rather than just relieving the pain, it belongs to the group of medicines called disease modifying antirheumatic drugs (DMARDS).

What benefit can you expect from your treatment?

Penicillamine does not work straight away. Reduced pain, stiffness and swelling may not be noticed for several months. The full effect may take up to 26 weeks. Other medicines may be given to improve your symptoms while waiting for penicillamine to work.

If you stop your penicillamine treatment for more than a few weeks there is a risk that your condition may worsen.

Treatment with penicillamine may be continued indefinitely as long as it is effective and no serious side effects occur.
How is penicillamine taken?

Penicillamine is taken by mouth in tablet form usually once or twice a day.

Treatment begins with a small dose (usually 125mg or 250 mg a day) and is increased slowly if there are no side effects in the first few weeks of treatment.

Generally the maintenance dose of penicillamine is between 125mg to 750mg a day depending on the response.

If you miss a dose take it as soon as you remember, but if you remember when it is almost time for your next dose take only the usual dose. Do not take a double dose.

Because the medicine binds to various foods it is important to take it on an empty stomach or at least 1 hour before, or 2 hours after, a meal.

It is also important not to take iron tablets, calcium, milk or antacids within 2 hours of taking penicillamine as they reduce the absorption of the medicine.

Penicillamine may be used with other arthritis medicines including:
- other DMARDs such as methotrexate
- steroid medicines such as prednisolone or cortisone injections into the joint
- anti-inflammatory medicines (NSAIDs) such as naproxen (Naprosyn) or ibuprofen (Brufen/Nurofen)
- simple pain medicines such as paracetamol.

Are there any side effects?

You might experience side effects with your treatment. Tell your doctor if you are concerned about possible side effects. A reduction in the dose may minimise side effects so that you can continue to take this treatment. Your doctor will advise on any dose changes that are necessary.

Most common possible side effects
- The most common side effect is a skin rash. This occurs in up to 15% of people taking penicillamine. The rash may be itchy. If the rash blisters, penicillamine will usually be stopped.
- Mouth ulcers may also occur. Alterations in taste are fairly common, but often disappear in a few weeks.
- There may be some degree of nausea (feeling sick) and loss of appetite at the beginning, but these feelings often pass. See your doctor if these effects persist.

Kidney function: In 5 to 20% of people penicillamine may affect the kidneys and may cause a leakage of protein into the urine. Regular urine tests will therefore be done during your treatment (see below). Traces of protein in the urine are usually not a problem, but larger amounts will usually mean the treatment will be stopped. You should tell your doctor if you have had kidney problems in the past.

Less common or rare possible side effects

There are some rare but potentially serious side effects with penicillamine.
- Blood counts: Penicillamine can cause a drop in the number of white blood cells, which are needed to fight infection. It can also cause a drop in the number of platelets, which help to stop bleeding. These effects occur in less than 5% of patients.

Regular blood tests aim to pick these problems up early when they occur. However, if you develop a sore mouth, mouth ulcers, easy bruising, nosebleeds, bleeding gums, breathlessness, infection or fever tell your doctor straight away.
- Very rare side effects include painful breasts or immune related disorders.

What precautions are necessary?

Blood tests
- Since the blood cells may be affected by penicillamine, you must have regular blood tests during your treatment. This is very important, as you may not get symptoms with these problems.
- Blood tests are particularly important during the first few months of treatment.
- As well as monitoring for side effects, blood tests help to monitor your condition to determine if the treatment is effective.
- You will be advised how often these tests are necessary. It may be fortnightly to begin with, and once every 1 to 3 months when a maintenance dose has been reached.
- Your general practitioner will be informed about the monitoring schedule. It is important to see your general practitioner if you have been asked to do so as they have an important role to play in monitoring your condition.

Urine tests
- It is important to have regular urine tests to check for effects on the kidney. Testing for
protein in the urine can be done at home using ‘dipsticks’.
- A record card or booklet may be provided to record the results of blood and urine tests.

**Use with other medicines**
- Penicillamine can interact with other medicines. You should tell your doctor (including your general practitioner, rheumatologist and others) about all medicines you are taking or plan to take. This includes over the counter or herbal or naturopathic medicines. You should also mention your treatment when you see other health professionals.

- Penicillamine can increase the risk for liver injury if given with isoniazid (INH) a medicine used for tuberculosis.

**Use in pregnancy and breastfeeding**
- Penicillamine should not be taken during pregnancy or when breastfeeding. If you are a woman of child bearing age you should use effective contraception while taking penicillamine.

**How to store penicillamine**
- Store penicillamine in a cool, dry place, away from direct heat and light (e.g not in the bathroom).
- Keep all medicines out of reach of children

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### Questions?
If you have any questions or concerns write them down and discuss them with your doctor.

### Your doctor’s contact details
If you are taking d-penicillamine you should see your rheumatologist regularly to make sure the treatment is working and to minimise any possible side effects.

### How to help us help you
**Sign up to the ARAD project now!**
The Australian Rheumatology Association collects information on how well these drugs work and how often they cause problems. The best way to get this information is from you!

**Contact us in any of the following ways:**
- **Email:** ARAD@monash.edu
- **Telephone:** 03 9508 3424
- **Visit our website:** www.ARAD.org.au

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The information in this sheet has been obtained from various sources and has been reviewed by the Australian Rheumatology Association. It is intended as an educational aid and does not cover all possible uses, actions, precautions, side effects, or interactions of the medicines mentioned. This information is not intended as medical advice for individual problems nor for making an individual assessment of the risks and benefits of taking a particular medicine. It can be reproduced in its entirety but cannot be altered without permission from the ARA.

The NHMRC publication: *How to present the evidence for consumers: preparation of consumer publications* (2000) was used as a guide in developing this publication.