NHS
Cambridgeshire and Peterborough
Clinical Commissioning Group

Shared care guideline

Penicillamine (Distamine) – Guidelines for its use in rheumatic diseases

Executive summary

- Penicillamine is used as a disease-modifying agent to induce and maintain a remission of rheumatoid arthritis. It is potentially toxic and therefore the drug must be monitored.
- This drug is now rarely prescribed. These guidelines are retained for patients who are established on it.
- The responsibilities of the hospital specialist, GP and patient for this shared care guideline can be found within this document (see section 11 below).

Sharing of care depends on communication between the specialist, GP and the patient or their parent/ carer. The intention to share care should be explained to the patient and accepted by them. Patients are under regular follow-up and this provides an opportunity to discuss drug therapy. The doctor/ healthcare professional who prescribes the medication has the clinical responsibility for the drug and the consequences of its use. Further information about the general responsibilities of the hospital specialist and GP can be found on the NHS Cambridgeshire and Peterborough CCG website.

1. Scope

Prescribing and monitoring by GPs.

2. Aim

This shared care guideline outlines the responsibility of primary and secondary care clinicians in managing penicillamine for use in rheumatoid arthritis.

3. Introduction

Penicillamine is used as a disease-modifying agent to induce and maintain a remission of rheumatoid arthritis. It is potentially toxic and therefore the drug must be monitored. This drug is now rarely prescribed. These guidelines are retained for patients who are established on it. These shared care monitoring guidelines have been approved by the East Anglia Rheumatology Society.

4. Abbreviations

CCG	clinical commissioning group
ESR	erythrocyte sedimentation rate
FBC	full blood count
GP	general practitioner
MSU	mid-stream urine
NSAID	non-steroidal anti-inflammatory drug
SPC	summary of product characteristics
WBC	white blood (cell) count

5. Dose and administration

Start with 125-250 mg daily for four weeks.
Increase by 125 mg daily monthly until remission occurs.
The maximum recommended dosage is 1000 mg daily

Remission usually occurs at 8 to 16 weeks.

Further information can be found in the SPC: http://www.medicines.org.uk/emc/medicine/9211

6. Adverse effects

- Rashes/ anorexia/ taste disturbance/ nausea.
- Bone marrow suppression, causing thrombocytopenia, neutropaenia and rarely anaemia. Warn patients to report sore throat, or abnormal bleeding/ bruising/rashes, mouth ulcer.
- Renal damage indicated by proteinuria/ haematuria on urinalysis.
- Rarely febrile reactions, myasthenia, drug-induced lupus.

Further information can be found in the SPC: http://www.medicines.org.uk/emc/medicine/9211

7. Cautions

- Care should be exercised in patients with renal insufficiency; modification of dosage may be necessary.
- Especially careful monitoring is necessary in the elderly since increased toxicity has been observed in this patient population regardless of renal function.
- Concomitant use of NSAIDs and other nephrotoxic drugs may increase the risk of renal damage – see section 9.
- Penicillamine should be used with caution in patients who have had adverse reactions to gold.
- Note that there are no restrictions on vaccinations in patients treated with penicillamine.

Further information can be found in the SPC: http://www.medicines.org.uk/emc/medicine/9211

8. Contraindications

- Hypersensitivity to penicillamine or any of the ingredients.
- Agranulocytosis, aplastic anaemia or severe thrombocytopenia due to penicillamine.
- Lupus erythematosus.
- Moderate or severe renal impairment.
- Penicillamine should not be administered to patients who are pregnant and **therapy should be stopped when pregnancy is confirmed or suspected,** unless considered absolutely essential by the specialist.

Further information can be found in the SPC: http://www.medicines.org.uk/emc/medicine/9211

9. Interactions

- Concomitant use of clozapine should be avoided - increased risk of agranulocytosis.
- Concomitant use of NSAIDs and other nephrotoxic drugs may increase the risk of renal damage.
- Iron supplements, zinc supplements and antacids may reduce absorption of penicillamine – do not take within 2 hours of penicillamine

Further information can be found in the SPC: http://www.medicines.org.uk/emc/medicine/9211.

10. Monitoring standards and actions to take in the event of abnormal test results/ symptoms

Monitoring standard	By whom	When/how often
FBC	Specialist	Prior to initiation
	GP	Fortnightly for the first eight weeks and thereafter monthly. They should also be carried out in the week after any dose increase.
Urgent FBC	GP	For patients developing significant infection - looking for leucopaenia.
ESR	GP	Monthly to help assess response to treatment.
Urinalysis	Specialist	Prior to initiation
	GP	Fortnightly for the first eight weeks and thereafter monthly. Also to be carried out in the week after any dose increase.
Ask patient about any sore throat, fever, infection, non-specific illness, unexplained bleeding and bruising, purpura, mouth ulcers or rashes.	GP	At each encounter with patient.
Record results in patient held booklet.	GP	At each encounter with patient.

Abnormal test result/ symptoms	Action by GP
Proteinuria 2+	Check MSU and treat if evidence of infection. If sterile and 2+ withhold drug and inform rheumatology team or specialist nurse. See section 12 for contact numbers.
WBC < 3.5 x10^9/l or neutrophils <2 x10^9/l	**Stop penicillamine** and inform rheumatology team or nurse practitioner. See section 12 for contact numbers.
Platelets < 150 x10^9/l	

Sore throat, abnormal bleeding or bruising, unexplained rash, oral ulceration, infection, fever	Check FBC; **if abnormal stop penicillamine** and inform rheumatology team or specialist nurse. See section 12 for contact numbers.

11. Shared care responsibilities

a. Hospital specialist:

- Initiate penicillamine and inform GP of dose. Note this drug is now rarely prescribed. These guidelines are retained for patients who are established on it.
- Send a letter to the GP requesting shared care for the patient.
- Inform the GP after each clinic attendance if there is any change to treatment or monitoring.
- Inform GP of patients who do not attend clinic appointments.
- To provide any advice to the patient/ carer when requested.

b. General practitioner:

- Agreement to shared care guideline by the GP.
- Prescribe penicillamine as directed by hospital specialist.
- Monitor patients on penicillamine as described in section 10.
- Report any adverse events to the hospital specialist, where appropriate, and as described in section 9.
- Request advice from the hospital specialist when necessary.

c. Patient or parent/ carer:

- Bring patient held booklet to each appointment with the hospital specialist or GP.
- Report to the hospital specialist or GP if they do not have a clear understanding of their treatment.
- Patients must not exceed the recommended dose.
- Patients must attend their scheduled clinic and blood test appointments (where relevant).
- Must inform other clinical staff that they are receiving treatment.
- Report any adverse effects to the hospital specialist or GP.

12. Contact numbers for advice and support

Cambridge University Hospitals NHS Foundation Trust		
Specialist	**Post**	**Telephone**

Dr Gavin Clunie	Consultant Rheumatologist	01223 216774 (secretary)
Dr Nicholas Shenker	Consultant Rheumatologist	01223 256883 (secretary)
Rheumatology advice line & rheumatology practitioners		01223 254933 Option 2
Patients' medicines helpline: Mon–Fri: 09:00 to 17:00 hrs medinfo@addenbrookes.nhs.uk		01223 217502

13. Equality and diversity statement

This document complies with the Cambridge University Hospitals NHS Foundation Trust service equality and diversity statement.

14. Disclaimer

It is **your** responsibility to check that this printed out copy is the most recent issue of this document.

15. Document management

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The information contained in this guideline is issued on the understanding that it is accurate based on the resources at the time of issue. For further information please refer to the most recent Summary of Product Characteristics http://www.medicines.org.uk/emc/medicine/9211