Shared Care Guideline

Drug	D-PENICILLAMINE	
Speciality	RHEUMATOLOGY	
Indication	RHEUMATOID DISEASE	
Overview	Penicillamine is a disease modifying anti-rheumatic drug. Monitoring is required, particularly for bone marrow suppression and proteinuria (immune complex nephritis).	
Hospital Specialist's responsibilities	**Initial Investigations:**	FBC, ESR/CRP, U&E, Creatinine, eGFR, LFTs & urine dipstick and urine protein-creatinine ratio. Assessment for comorbidities such as lung disease and occult viral infection
	Initial regimen:	125 to 250 mg daily, increased to maximum 1.5gram daily
	Clinical Monitoring:	For adverse effects (specific enquiry skin of rash or mouth ulcers) and usual disease management.
	Frequency:	As required, typically every 3-6 months once stable
	Safety Monitoring and frequency:	FBC, ESR/CRP,U&E, creatinine, eGFR, LFTs & urinalysis fortnightly for 6 weeks, then monthly for 3 months, then every 3 months thereafter. Monitor fortnightly for 6 weeks following any dose increase.
	Prescribing arrangements:	First 3 months in hospital until stable, then transferred to GP.
	Documentation:	Clinic letters and results to GP. Separate patient information and offer patient-held shared care diary.
GP's Responsibilities	**Maintenance Prescribing:**	125mg to 1.5g daily, according to specialist advice
	Clinical monitoring	For adverse effects (specific enquiry of skin rash or mouth ulcers) and usual disease management.
	Frequency	As required and determined by patient symptoms
	Safety Monitoring	FBC, ESR/CRP, U&E, creatinine, eGFR, LFTs, urinalysis
	Frequency:	3 monthly. Monitor fortnightly for 6 weeks following any dose increase.
	Duration of Treatment:	Long-term as recommended by specialist.
	Documentation:	Practice records. Correspondence with specialist as required. Copies of blood results to specialist using shared care diary or available via webICE.

Adverse Events	Action:
WCC ↓ <3.5 x10^9/L, Neutrophil count ↓ <1.6 x10^9/L, Platelet count ↓ <140 x10^9/L	Withhold, repeat FBC & discuss with specialist
↓ trend in WCC / platelet count	Discuss with specialist
eGFR < 60ml/min	Withhold drug, discuss with specialist
Abnormal bruising or severe sore throat	Check FBC; withhold until results available & discuss with specialist
1+ proteinuria	Check urine protein-creatinine ratio.
Urine protein-creatinine ratio <50 mg/mmol.	Continue treatment and repeat urine protein-creatinine ratio before next injection
2+ proteinuria or more or urine protein-creatinine ratio >50 mg/mmol	Stop penicllamine.Check MSU: If infection present treat appropriately. If MSU sterile and 2+proteinuria or more persists, check protein/creatinine ratio, withhold drug and discuss with specialist
Urine protein-creatinine ratio >100 mg/mmol.	Indicates severe proteinuria. Stop Penicllamine and discuss with specialist.
Loss of taste can occur about 6 weeks after treatment is started but usually returns 6 weeks later irrespective of whether treatment is discontinued	

Contact Details

Name:	Sr Elaine Doyle	Sr Cath Hutton	Specialist Nurse	Specialist Nurse
Address:	Rheumatology Dept, JCUH	Rheumatology Dept,FHN	Rheumatology Dept,UHNT	Rheumatology Dept,UHH
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Further Information	

Intercurrent Infection
During an acute infection, Penicillamine can be continued.

Adverse Effects
Anorexia; fever; nausea; proteinuria; rash. Other AEs include: blood disorders; bronchiolitis; cholestatic jaundice; dermatomyositis; glomerulonephritis; Goodpasture's syndrome; haemolytic anaemia; leucopenia; lupus erythematosus; myasthenia gravis; nephrotic syndrome; neuropathy; pancreatitis; pemphigus; pneumonitis; polymyositis; pulmonary haemorrhage; Stevens-Johnson syndrome; taste loss; urticaria; vomiting.

Proteinuria
Proteinuria, associated with immune complex nephritis, occurs in up to 30% of patients, but may resolve despite continuation of treatment. Treatment may be continued provided that renal function tests remain normal, oedema is absent, and the 24-hour urinary excretion of protein does not exceed 1 gram/day (decision by specialist).

Vaccinations
Live vaccines are not recommended, although the live shingles vaccine is appropriate in some patients (refer to Green Book for advice). We recommend annual flu vaccination and Pneumococcal vaccination in line with current guidance.(see JCVI Green Book). If a patient is exposed to shingles or chickenpox, and lacks immunity to varicella-zoster virus, passive immunisation may be required (contact Rheumatology).

Fertility Issues
Fetal abnormalities reported rarely; avoid in pregnancy if possible.

If you are thinking about discontinuing treatment please discuss with the Consultant or Rheumatology staff first.

If the patient has any problems with their medication, adverse effects or an exacerbation of their disease requiring an earlier appointment in the Rheumatology Department, please contact the rheumatology specialist nurse practitioners using the contact details below.

Reference BSR and BHPR guideline for the prescription and monitoring of non-biologic disease-modifying anti-rheumatic drugs. Rheumatology 2017 ; 56 : 865-8.