

Riluzole shared care agreement & guidelines

Drug Speciality	RILUZOLE	
	NEUROLOGY	
Overview	Riluzole is currently the only drug licensed for treating ALS in the UK. The licensed indication is to extend life or the time to mechanical ventilation for individuals with ALS. Riluzole is rarely associated with neutropenia (1:1000) and very rarely hepatitis.	
Hospital Specialists responsibilities	Initial Investigations:	U&Es, LFTs, FBC
	Initial regimen:	Riluzole 50mg twice a day (tablet or oral suspension)
	Clinical Monitoring:	For adverse effects and usual disease management
	Frequency:	As required, typically every 3 months
	Safety Monitoring:	U&Es, LFTs, creatinine, FBC - Initial (pre-treatment) – monthly for first 3 months
	Prescribing details:	First 3 months from hospital then prescribing responsibility taken over by GP
	Documentation:	Clinic letter to GP including timing of blood investigations required & necessary forms. Separate patient information.
GP's Responsibilities	Maintenance Prescribing:	Riluzole 50mg twice daily (tablet or oral suspension)
	Clinical monitoring	For adverse effects and usual disease management
	Frequency	As required
	Safety Monitoring	U&Es, LFTs, Gamma GT, Creatinine, FBC
	Frequency:	At months (1,2,3), 6,9 & 12 (6 monthly thereafter)
	Duration of Treatment:	Long-term, until no longer felt appropriate
	Documentation:	Practice records, correspondence with specialist as required, copies of blood results to specialist
Adverse events	Adverse Events	Action:
	LFT ↑ 3-5 x upper limit of normal (ULN)	Occurs in 7%: monitor LFTs weekly
	LFT ↑ >5x ULN or jaundice	Stop Riluzole & discuss with specialist
	WCC ↓ 2.0 to 4.0	Monitor weekly
	WCC ↓ < 2.0	Stop Riluzole & discuss with specialist
	Creatinine ↑ > 200	Discuss with specialist
Contact details	Contact Details	
	Dr Janine Evans Consultant Neurologist	Anthony Hanratty MND Nurse Specialist
	Middlesbrough MND Care Centre, JCUH 01642 854318 stees.mnd@nhs.net	