**Riluzole**

**Neurology shared care guideline**

---

### Specialist details

Name: __________________________
Location: ________________________
Tel: ____________________________

### Patient identifier

Date: ____________________________

---

**Introduction**

**Licensed indications:** Riluzole is indicated to extend life or the time to mechanical ventilation for patients with amyotrophic lateral sclerosis (ALS). It should only be initiated by specialist physicians with experience in the management of motor neurone diseases.

**Adult dosage and administration:** 50mg twice daily (every 12 hours).

**Available as:** 50mg tablets, 5mg/mL oral suspension (all dispensed via pharmacy department, Royal Group of Hospitals).

The liquid formulation should be reserved for use in patients identified by the clinical team as being at risk of dysphagia. For administration via feeding tube, it may be preferable to crush and flush the tablets.

---

**Hospital specialist responsibilities**

- Assess patient is suitable for treatment with riluzole.
- Assess patient's current repeat medications for potential significant interactions with the new treatment and discuss with GP if any concerns.
- Prescribe riluzole.
- Arrange ongoing monitoring with the patient’s GP.
- Provide patient/carer with relevant written information on use, side-effects and need for monitoring of medication.
- Provide shared care monitoring record booklet if required.
- Baseline tests:
  - LFTs
  - FBC
  - U&E
- Review results of safety monitoring and request additional tests as required.
- Monitor disease response to treatment and need to continue therapy.
- Continue to review the patient at agreed specified intervals, sending a written summary to the GP whenever the patient is reviewed.
- Provide any other advice or information for the GP if required.

---

**GP responsibilities**

- Arrange and record ongoing monitoring as agreed with specialist:
  - **LFT:** monthly for first 3 months then every 3 months during the remainder of the first year, then periodically thereafter.
  - **FBC:** if the patient reports any febrile illness; ask about the presence of rash, oral ulceration at each visit.
- Report any adverse drug reactions to initiating specialist and usual bodies (eg. MHRA / CHM).
- Ensure no significant drug interactions with other medicines.

---

**Withhold riluzole and contact specialist if:**

- WCC < 3.5 x 10^9/L
- Neutrophils < 1.5 x 10^9/L
- AST / ALT > 3 times the upper limit of normal

Please note: a rapidly increasing or decreasing trend in any values should prompt caution and extra vigilance.
Adverse effects, precautions and contraindications

Alterations in liver function tests are common.  
Tachycardia is commonly reported.  
Nausea; vomiting, abdominal pain and diarrhoea are commonly reported.  
Headache, dizziness, oral paraesthesia and somnolence are common.  
Neutropenia has been reported. Patients should be advised to report any febrile illness to their doctor.  
Interstitial lung disease has been reported; if patient presents with dry cough and/or dyspnoea, riluzole should be withheld and the initiating specialist contacted.

Contraindications include:
- Hypersensitivity to riluzole or to any of the excipients.  
- Hepatic disease or baseline transaminases greater than 3 times the upper limit of normal.  
- Patients who are pregnant or breastfeeding.

Common drug interactions

There have been no clinical studies to evaluate the interactions of riluzole with other medicinal products.

Communication

For any queries relating to this patient’s treatment with riluzole, please contact the MND Network Co-ordinator named below:

Name:  
Location:  
Tel:  

This information is not inclusive of all prescribing information and potential adverse effects. Please refer to full prescribing data in the SPC or the BNF

Date Prepared: December 2017  
Date of review: December 2022