NOTTINGHAMSHIRE AREA PRESCRIBING COMMITTEE
SHARED CARE PROTOCOL AGREEMENT

RILUZOLE FOR ADULTS WITH MOTOR NEURONE DISEASE

REFERRAL CRITERIA

- Prescribing responsibility will only be transferred when it is agreed by the specialist and the patient's primary care prescriber.

REFERRAL PROCESS

- The request for shared care should be accompanied by individual patient information, outlining all relevant aspects of the patients care and which includes direction to the information sheets at www.nottsapc.nhs.uk.

- If the GP does not agree to share care for the patient then he/she will inform the Specialist of his/her decision in writing within 14 days.

- In cases where shared care arrangements are not in place or where problems have arisen within the agreement and patient care may be affected, the responsibility for the patients' management including prescribing reverts back to the Specialist.

BACKGROUND INFORMATION

Riluzole is a glutamate antagonist, which is licensed and indicated to extend life or the time to mechanical ventilation in patients with the amyotrophic lateral sclerosis (ALS) form of MND.

CONDITION TO BE TREATED

Motor neurone disease (MND) is characterised by progressive degeneration of the motor neurones of the brain, brain stem or spinal cord. Depending on the site of the lesions, characteristic signs may include spasticity, muscle stiffness, brisk or diminished reflexes, muscle wasting and fasciculation, and both flaccid and/or spastic weakness. It has a median survival of 2-5 years. A multidisciplinary team staffs the motor neurone disease clinic at QMC.

AREAS OF RESPONSIBILITY

Specialist's Roles and Responsibilities

1. The specialist will confirm the working diagnosis.
2. The specialist will recommend a regime and prescribe for the first three months of treatment.
3. The specialist will check full blood count and liver function tests monthly for first three months
4. The specialist will suggest that shared care may be appropriate for the patient's condition.
5. The specialist will ensure that the patient has an adequate supply of medication (usually 28 days) until shared care arrangements are in place. Further prescriptions will be issued if, for unseen reasons, arrangements for shared care are not in place at the end of 28 days. Patients should not be put in a position where they are unsure where to obtain supplies of their medication.
6. If shared care is considered appropriate for the patient, and the patient's treatment and condition are stable, the specialist will contact the GP.
7. The specialist will provide the patient's GP with relevant patient information as described in the referral process above.
8. Review patients annually and send a written summary within 14 days to the patient's GP.
9. The specialist team will be able to provide training for primary care prescribers if necessary to support the shared care agreement.
10. Contact details for primary care prescribers for during working and non- working hours will be made available
11. Details for fast track referral will be supplied.
12. The specialist will provide the patient with details of their treatment, follow up appointments, monitoring requirements and nurse specialist contact details.

Primary Care Prescribers Roles and Responsibilities

1. Ensuring that he/she has the information and knowledge to understand the therapeutic issues relating to the patient's clinical condition.

2. Undergoing any additional training necessary in order to carry out a practice based service.
3. Agreeing that in his / her opinion the patient should receive shared care for the diagnosed condition unless good reasons exist for the management to remain within secondary care.
4. Prescribing the maintenance therapy in accordance with the written instructions contained within the GP information sheets, and communicating any changes of dosage to the patient.
5. Administration of influenza and pneumococcal vaccinations as appropriate.
6. Reporting any adverse effect in the treatment of the patient to the consultant.
7. The GP will ensure that the patient is monitored according to the Nottinghamshire Area Prescribing Committee shared care agreement for riluzole and will take the advice of the referring consultant if there are any amendments to the suggested monitoring schedule.
8. The GP will ensure that the patient is given the appropriate appointments for follow up and monitoring, and that defaulters from follow up are contacted to arrange alternative appointments. It is the GPs responsibility to decide whether to continue treatment in a patient who does not attend appointments required for follow up and monitoring. As a guide, a telephone or written reminder should be sent to the patient if follow up is 1-2 weeks late. A telephone reminder is necessary if follow up is 3 weeks late. A written letter to stating that medication will be stopped and consultant informed is necessary if follow up is 4 weeks late.

Community Pharmacist Roles and Responsibilities
1. Professionally check prescriptions to ensure they are safe for the patient and contact the GP if necessary to clarify their intentions.
2. Fulfill legal prescriptions for medication for the patient unless they are considered unsafe.
3. Counsel the patient on the proper use of their medication.
4. Advise patients suspected of experiencing an adverse reaction to their medicines to contact their GP.

Patient's Roles and Responsibilities
1. Take their medication as agreed, unless otherwise instructed by an appropriate healthcare professional.
2. Attend all follow-up appointments with GP and specialist. If they are unable to attend any appointments they should inform the relevant practitioner as soon as possible and arrange an alternative appointment.
3. Inform all healthcare professionals of their current medication prior to receiving any new prescribed or over-the-counter medication.
4. Report all suspected adverse reactions to medicines to their GP.
5. Store their medication securely away from children.
6. Read the information supplied by their GP, specialist and pharmacist, and contact the relevant practitioner if they do not understand any of the information given.

A patient information leaflet is available from the MND association.

Support and Advice -The Nottingham MND Care Centre
Dr. Saam Sedehizadeh. Tel. 0115 969 1169 secretary extension 61752

MND Specialist Nurses: Erica Littleworth 0781 226 8289 e.littleworth@nhs.net
Alyson Halliday 0115 924 9924 ext. 61792
Louise Dudey 0781 227 0052

Out of Hours Via on call Neurology SpR at QMC

Version Control- **Riluzole for Adults with Motor Neurone Disease**			
Version	Author(s)	Date	Changes
2.1	Shary – Specialist Interface and Formulary Pharmacist	05/02/2021	Format and version control