

Advice Regarding Riluzole Supplies in the Community

Background:

We have shared care arrangements in place for [riluzole](#) across SY, however we have recently become aware of problems with supply of generic riluzole such that it is not available via any of the wholesalers in primary care.

There are however, supplies of the branded product Rilutek® which is available at a comparatively high price of approximately £330 a month, (compared to £8.69 a month for generic riluzole), but without a price concession being offered, supplies via community pharmacy are untenable.

The neurology specialists in Sheffield are therefore being contacted by patients for supplies from them as patients have been unable to source medication in the community. We have raised this supply issue / no price concession with the DHSC and are awaiting feedback.

Recently we have also become aware of an Oro dispersible formulation of riluzole: [Emylif®](#), which is available at wholesalers in the community and costs £168 a month but we are waiting for Emylif®, to be added to SystmOne / EMIS.

[Teglutik® 5 mg / ml oral suspension](#) is also another option if patients can manage a change in formulation and this equates to approximately £200 a month.

While generic riluzole supply problems continue in the community,

Suggested Actions are:

- Community pharmacists to contact prescribers to temporarily amend prescription to either Emylif®, Rilutek® or Teglutik®.
- Primary care clinicians to amend prescription to either Emylif®, Rilutek® or Teglutik®; liaise with community pharmacist to confirm supplies / liaise with patient etc, if patients report that unable to get supplies from community pharmacy.
- Once supplies of generic riluzole return into stock, to switch patients back to generic.

Sharron Kebell
Specialised Commissioning Pharmacist
South Yorkshire ICB- Sheffield place
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