

## Patient Preferences and Adherence to Different Formulations of Riluzole in ALS: A Survey-Based Study

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### Background:

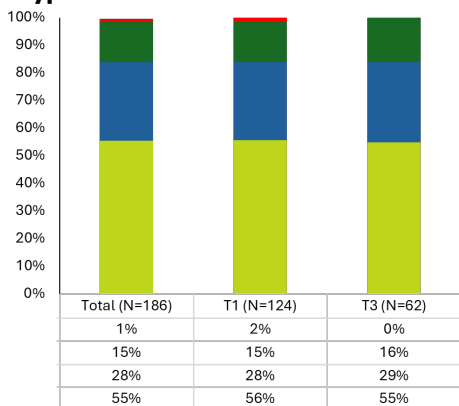
Riluzole is the only approved oral disease-modifying treatment for Amyotrophic Lateral Sclerosis (ALS). It is available in three formulations: orodispersible film (Emylif), tablets (Rilutek), and oral suspension (Teglutik). Understanding patient preferences and adherence to these formulations is crucial to optimizing treatment strategies, particularly in patients with swallowing difficulties.



### Methods:

We conducted a survey among ALS patients to assess the use, adherence, and perception of different riluzole formulations. The questionnaire investigate administration modalities, satisfaction, side effects, and factors influencing treatment discontinuation.

### Type of Riluzole formulation used



■ Emylif ■ Rilutek ■ Teglutik ■ None (Figure 1)

### Results:

A total of 186 patients were recruited, 78% with spinal onset, 22% with bulbar onset, with a median age of 65 years (IQR:59-69). While 59.4% of Emylif users self-administered the drug, 25% required caregiver assistance. The need for scissors to open the packaging was noted by 16% of users. Rilutek was mostly taken as whole tablets (82.9%), but 20.2% of patients reported crushing them before administration, highlighting potential swallowing difficulties. Teglutik was commonly administered with a syringe (58.8%). We evaluated the patients at baseline (T0), after three months (T3), and after six months (T6) (Figure 1). Adherence was generally high, with 82.4% reporting regular intake in the past two weeks. However, 11.8% missed the dose on the day before the survey. The main reasons for switching formulations included physician recommendation (33.3% for Teglutik, 69.5% for Rilutek, and 42.9% for Emylif) and not tolerable side effects (42.9% for Emylif, 2.8% for Rilutek, and 22.2% for Teglutik) (Figure 2).

### Adverse events

Symptom	SYRUP (%)	TABLET (%)	FILM (%)
Lips tingling/numbness/burning	11,1	1,9	12,6
Oral cavity tingling/numbness/burning	11,1	1,9	23,3
Throat burning	11,1	1,9	9,7
Tongue tingling/numbness/burning	7,4	15,1	34
Fatigue	7,4	3,8	2,9
Diarrhea	7,4	3,8	6,8
Nausea	3,7	3,8	7,8
Vomiting	0	1,9	4,9
None	66,7	71,7	38,8

(Figure 2)

### Conclusions:

While all riluzole formulations were generally well-accepted, the orodispersible film presented specific administration challenges and side effects. The need for crushing Rilutek in some patients suggest that dysphagia remains a relevant concern in ALS treatment. Tailoring riluzole formulation choice to individual patient needs is essential to optimizing adherence and patient comfort.