DERBYSHIRE JOINT AREA PRESCRIBING COMMITTEE (JAPC)

JAPC Prescribing guideline - Sodium Oxybate for adults with narcolepsy with cataplexy

Existing and new patients ≥19 years of age	**CCG commissioned**
Patients up to the age of 18 years of age	**NHSE commissioned**

JAPC has classified **Sodium Oxybate** as **RED** - CCG commissioned for adult patients with narcolepsy with cataplexy, through the specialist sleep centres.

Criteria for commissioning of sodium oxybate in adult patients

- Patients presenting with narcolepsy with cataplexy according to International Classification of sleep disorders 3 (ICSD) criteria for Narcolepsy Type 1 **AND**
- Patients ≥ 19 years old **AND**
- Where patients have co-morbidities, which are also affecting sleep, these should be managed and adequately treated (for example moderate to severe obstructive sleep apnoea or restless legs syndrome) **AND**
- Failure to respond to non-pharmacological treatments consisting of behavioural and environmental adaptations, for example planned naps **AND**
- Inadequate response (within 3 months) to, or intolerable adverse effects from, or contra-indicated use of, more than one stimulant for narcolepsy, *and* more than one anticataplectic agent **AND**
- Assessed as being able to benefit from sodium oxybate via a specialist sleep centre

The patient should be fully consulted at all stages of the process and should be fully involved in the decision on appropriate treatment options.

Assessing need for ongoing treatment

- Patients who show signs of serious adverse events should discontinue therapy.
- Improvements in narcolepsy and/ or cataplexy should be determined by expert clinical review, which will include the use of the Epworth Sleepiness Scale and an assessment of symptomatic/quality of life improvements.
- Discontinue if there is inadequate response at 3 months for both cataplexy and narcolepsy. Measurements should ideally be compared to scores prior to sodium oxybate treatment (see **Appendix 2** for definitions). Expert clinical review and patient history will also contribute to this assessment.

- Patients on established therapy should be reviewed at least annually if stable (more frequently if not) to ensure continued benefit.

- Trial withdrawal periods can be considered if this is clinically appropriate

Appendix 1: Patient cohort, commissioning responsibility and relevant policy/guidance

Patient Cohort	Commissioner	Policy/Guidance
Child <19 years (>40kg)	NHS England	NHS England Clinical Commissioning Policy: Sodium oxybate for symptom control of narcolepsy with cataplexy (children)
Adult ≥ 19 years (transitioning from paediatric care)	CCG	RMOC Advisory Statement (interim position until NHS England/NHS Improvement transitioning framework published)
Adults ≥ 19 years (sodium oxybate treatment naïve)	CCG	RMOC Advisory Statement
Adults ≥ 19 years currently receiving sodium oxybate treatment	CCG	Review appropriateness of continued treatment as per RMOC Advisory Statement

Appendix 2: Measuring Response to sodium oxybate treatment

Cataplexy
At least one cataplexy score (either severity or frequency) should improve after 3 months of therapy. Measurements should be compared to scores prior to sodium oxybate treatment.

Severity of cataplexy
1 = moderate weakness
2 = can maintain posture with external support
3 = loses posture and falls to the ground

Frequency of cataplexy
0 = < 1 episode per year
1 = ≥ 1 attack per year
2 = more than one attack per month
3 = > 1 attack per week
4 = > 1 per day

Narcolepsy
Improvements in narcolepsy should be determined by expert clinical review, which will include the use of the Epworth Sleepiness Scale and an assessment of symptomatic/quality of life improvements.

The full RMOC document can be obtained from https://www.sps.nhs.uk/