

Thames Valley Priorities Committee Commissioning Policy Statement

Policy No. TVPC99 **Sodium oxybate for narcolepsy with cataplexy in adults**

**Recommendation made by
the Priorities Committee:** **June 2020**

Date of issue: **October 2020**

Thames Valley Priorities Committee has considered the national guidance and evidence for the use of sodium oxybate for narcolepsy with cataplexy in adults. Due to limited evidence for clinical and cost effectiveness for the use of sodium oxybate compared to other treatments, sodium oxybate is not normally funded for adult patients. Patients with narcolepsy with cataplexy, who have received sodium oxybate commissioned by NHS England in paediatric care and are transitioning to adult services, should continue to do so provided that there is a demonstrable ongoing clinical need and benefit.

Patients on established therapy should be reviewed at least annually if stable (more frequently if not) to ensure continued benefit¹:

- 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 an inadequate response to treatment. Expert clinical review and patient history will contribute to this assessment.
- Trial withdrawal periods can be considered if this is clinically appropriate.

¹ Regional Medicines Optimisation Committee (October 2019) Advisory Statement: Sodium Oxybate – Commissioning in adult patients with narcolepsy with cataplexy. Clinical Decision Criteria.
<https://www.sps.nhs.uk/articles/rmoc-sodium-oxybate-in-adult-patients/>

NOTES:

- Potentially exceptional circumstances may be considered by a patient's CCG where there is evidence of significant health status impairment (e.g. inability to perform activities of daily living) and there is evidence that the intervention sought would improve the individual's health status.
- This policy will be reviewed in the light of new evidence or new national guidance, e.g. from NICE.
- Thames Valley clinical policies can be viewed at <http://www.fundingrequests.ccsu.nhs.uk/>