

Narcolepsy Prescribing Guidance for Primary Care Practitioners

This two-page quick reference guide, written by the Respiratory Support and Sleep Centre at Royal Papworth Hospital, aims to assist Primary Care Practitioners to understand the East of England Treatment Pathway for Narcolepsy.

What is Narcolepsy?

Narcolepsy is a chronic sleep boundary disorder that affects the control of sleep and wakefulness. It has an estimated prevalence is 40 per 100,000 UK population.

The brain's impaired ability to regulate normal sleep/wake cycles leads to disturbed night-time sleep and excessive daytime sleepiness. Symptoms include uncontrollable sleep attacks, episodes of conscious collapse (cataplexy), vivid dream-like episodes of seeing, hearing and feeling just before sleep (hypnagogic hallucinations), dream enactment, and sleep paralysis.

About 70% of patients with narcolepsy also have cataplexy which presents as a transient bilateral attack of muscle weakness due to sudden loss of muscle tone, typically lasting less than 2 minutes. Episodes are often precipitated by strong emotional responses, such as laughter, surprise, fear, or anger. Consciousness is retained unless an episode evolves into sleep. Approximately 30% of cases are severe enough to warrant anti-cataplectic treatment.

Diagnosis and Management

A diagnosis of narcolepsy should be made by a Specialist and evidenced by polysomnography. Sleep services for the East of England Region are provided by the Respiratory Support and Sleep Centre at Royal Papworth Hospital.

Up to 10% of patients diagnosed with narcolepsy manage their condition with lifestyle measures such as [good sleep hygiene practices](#).

The majority of patients requiring medication will be managed under a shared care agreement between the Specialist and the patients GP. Prescribing recommendations are made from a [formulary of sleep medication](#) which is common to all Integrated Care Systems across the region. With the exception of sodium oxybate, all funding for ongoing maintenance medication listed within the Regional Sleep Formulary sits with primary care.

Most medication used to manage narcolepsy and cataplexy is used off-label (i.e. a medicine used for an indication not included in the licence) which naturally leads to gaps in the supporting evidence base. There are no head-to-head trials of comparative efficacy between the different treatment options and treatment pathways have evolved based on global experience and recommendations published by expert bodies.

A history and physical examination is performed in the first month of therapy and afterwards as needed to monitor symptoms and adverse effects of treatment. Patients are followed up every 6 to

12 months to re-evaluate the social support network, monitor symptoms, and assess medicine-related adverse effects (e.g., headaches, hypertension, rashes, etc) and efficacy.

Residual sleepiness on treatment is monitored using the Epworth Sleepiness Scale, repeat polysomnography, sleep latency and maintenance of wakefulness tests. It is important to distinguish residual sleepiness due to treatment failure from the symptoms generated by co-morbid conditions such as obstructive sleep apnoea.

Useful Links

1. [Protocol for the Management of Patients Receiving Sodium Oxybate for Narcolepsy](#)
2. [SCG - Dexamfetamine - excessive sleepiness associated with Narcolepsy](#)
3. [SCG - Methylphenidate - excessive sleepiness associated with Narcolepsy](#)
4. [SCG - Modafinil - Excessive sleepiness associated with Narcolepsy](#)
5. [TA758: Solriamfetol for treating excessive daytime sleepiness caused by Narcolepsy](#)

Document ratification details

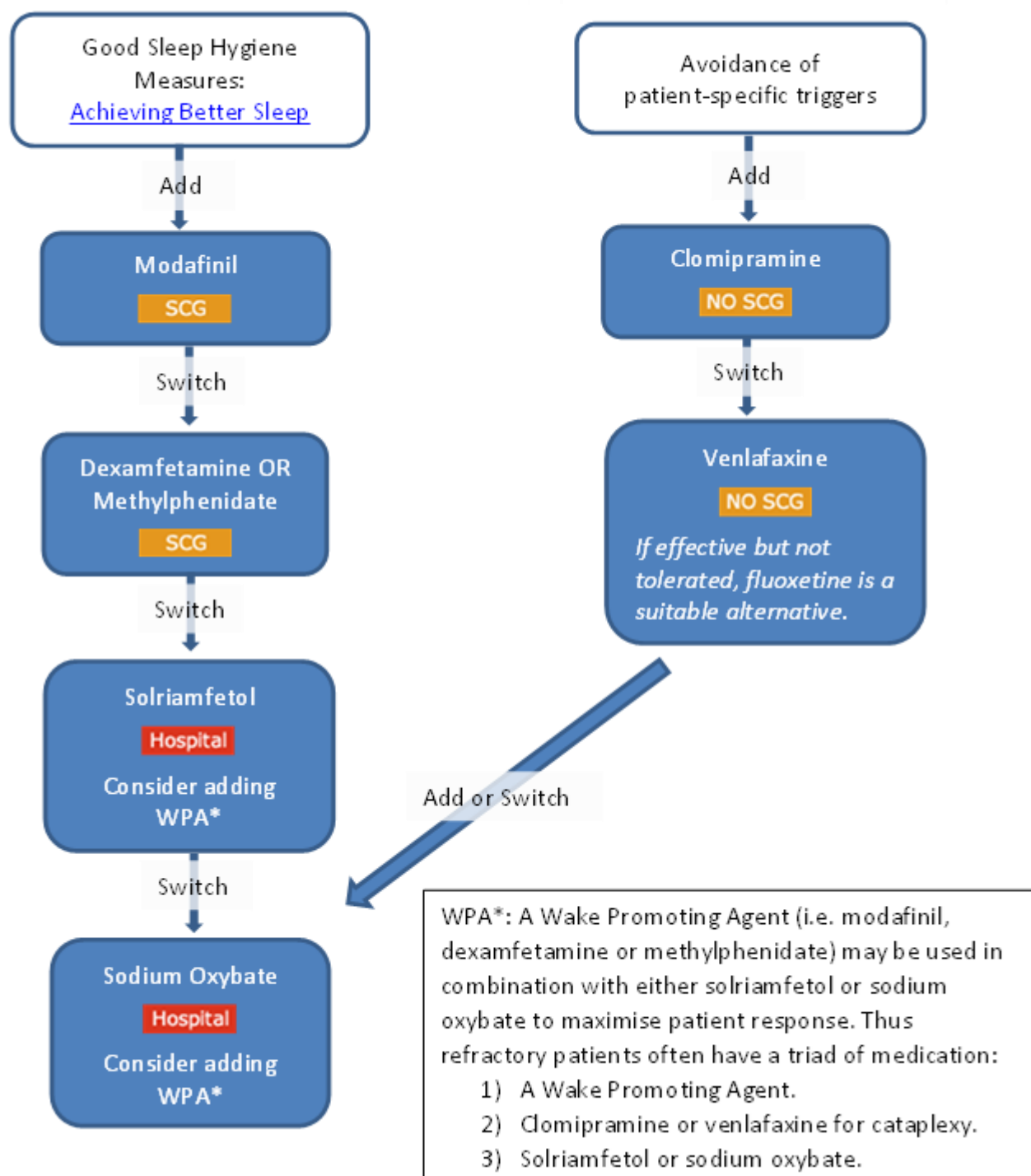
Ratification Process	Details
Authored by:	Cambridgeshire and Peterborough Integrated Care System
Ratified by:	Cambridgeshire and Peterborough Joint Prescribing Group
Date ratified:	December 2022
Review date:	December 2025
Version number:	1

Flow Chart for the treatment of Narcolepsy with or without Cataplexy

Treatment of Narcolepsy

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Treatment of Cataplexy



Patient Support Group: [Narcolepsy UK](#)

[Good sleep hygiene measures: Achieving Better Sleep patient guide.](#)

NO SCG Formulary - Specialist initiation without shared care guidance.

SCG Formulary - Specialist initiation with shared care guidance.

Hospital Restricted - Prescribing and monitoring to remain with the specialist service. Not to be prescribed in Primary Care.