Pathway for the pharmacological management of excessive daytime sleepiness due to narcolepsy

Note: Modafinil, methylphenidate (immediate release and XL), dexamphetamine and sodium oxybate are APC Amber 3 category – initiation and minimum 6 months’ supply by the sleep centre (specialising in Narcolepsy). GPs are not expected to initiate these treatments but may be asked to take on prescribing in line with APC recommendations under the shared care guideline. Pitolisant is APC RED category (hospital only) – initiation and ongoing prescribing will be by the sleep service, GPs will not be asked to prescribe pitolisant.

**Diagnosis of:**
- Narcolepsy (with or without cataplexy)

**All patients:**
- Reinforce good sleep hygiene
- Refer to Narcolepsy UK

**Ongoing recommendation of treatment regimen:**

**Excessive daytime sleepiness, ESS>12/24**

**First line therapy:**
- Modafinil 50-400mg daily for 3 months, and review efficacy and patient tolerability

Review by specialist in 3-6 months.
Regular follow up in clinic or via telephone by the sleep pharmacist between consultant appointments.

**No significant improvement* or adverse reaction to modafinil:**
1. **Stop** Modafinil
2. **Initiate:**
   - 2a: Methylphenidate XL 18-72mg mane
   - 2b: Methylphenidate immediate release 10-60mg daily in divided doses
   - 2c: Dexamphetamine 10-60mg daily in divided doses

Review by specialist in 3-6 months
Regular follow up in clinic or via telephone by the sleep pharmacist between consultant appointments.

**Improvement but residual sleepiness**
1. Continue/titrate Modafinil
2. Add methylphenidate or** dexamphetamine

Review by specialist in 3-6 months.
Regular follow up in clinic or via telephone by the sleep pharmacist between consultant appointments.

**No significant improvement* or adverse reaction:**
1. Stop ineffective/not tolerated treatment

Consider last line therapies as appropriate:
- Sodium oxybate 4.5–9g at night in TWO divided doses
  (for patients with cataplexy only who meet specified criteria)
- Pitolisant 4.5-36mg mane
  (used if refractory to all other above treatments)
  Note: pitolisant is for prescribing by the hospital only

Review by specialist in 3-6 months.
Regular follow up in clinic or via telephone by the sleep pharmacist between consultant appointments.

* A significant improvement is a change in ESS of 3 or more.
** Methylphenidate and Dexamphetamine should not be prescribed concomitantly.