

# RCPCH Working Party on Sleep Physiology and Respiratory Control Disorders in Childhood

## Lay Summary 8 – Narcolepsy

### What is narcolepsy?

Narcolepsy is a disorder of the regulation of sleep and wakefulness, which can be difficult to diagnose, especially in childhood. The main symptoms are shown in the box below. Not all of the features may be present at once. It is a moderately common condition, occurring in about 1 in 2000 of the adult population, and is probably under-recognised in children.

#### Main features of narcolepsy

- Excessive daytime sleepiness
- Cataplexy (sudden loss of muscle tone induced by strong emotions)
- Hypnagogic hallucinations (vivid dream-like visual images before falling asleep)
- Sleep paralysis (a feeling of being unable to move upon awakening)
- Night sleep disturbance (broken sleep)

### How can we diagnose narcolepsy?

The traditional tests for narcolepsy involve a detailed overnight sleep study (polysomnography) with assessment of sleep staging, followed by multiple sleep latency tests. For more details of the tests, please see Lay Summary 1. In patients with a characteristic history of cataplexy a very low level of a chemical called orexin or hypocretin-1 in the fluid surrounding the brain and spinal cord (cerebrospinal fluid) is strongly suggestive of narcolepsy.

If there is a clinical suspicion of narcolepsy then referral to a specialist centre with expertise in the diagnosis and management should be made.

### Management

The management should be individualised for every patient and includes medical treatment with stimulant drugs such as modafinil, coupled with lifestyle adjustments, and education of carers and teachers about the condition. It should be supervised by a centre with expertise in the condition.